DADD Online Journal

Research to Practice

Focusing on individuals with
autism, intellectual disability and other developmental disabilities

Volume 11 Number 1 DADD December 2024

DADD ONLINE JOURNAL

Journal of the Division on Autism and Developmental Disabilities
Council for Exceptional Children

The ***DADD Online Journal*** integrates research and practice, reflecting the need for evidence-based and practice informed strategies and interventions within this diverse field. Topics include: Autism Spectrum Disorder, Assistive & Adaptive Technology, Early Childhood, Intellectual Disability, Mental Health, Multiple Disabilities, Paraprofessionals, Employment, Post-Secondary, and Transitions.

DADD Online Journal (ISSN 2377-3677), Volume 11, Number 1, December 2024, Copyright 2024 by the Division on Autism and Developmental Disabilities, The Council for Exceptional Children, 3100 Clarendon Blvd., Suite 600, Arlington, VA 22201-5332.

Division on Autism and Developmental Disabilities

Council for Exceptional Children

The purposes of this organization shall be to advance the education and welfare of persons with autism and developmental disabilities, research in the education of persons with autism and developmental disabilities, competency of educators in this field, public understanding of autism and developmental disabilities, and legislation needed to help accomplish these goals. The Division shall encourage and promote professional growth, research, and the dissemination and utilization of research findings.

DADD Online Journal

VOLUME 11 NUMBER 1 DECEMBER 2024

Research Informed Practice in Autism, Intellectual Disability, and Developmental Disabilities **1**
STANLEY H. ZUCKER, JESSICA MATUS, JESSE FLEMING, and ELIZABETH HARKINS

Empowering Partnership: Parental Perspectives of Parent-Teacher Engagement in IEP Processes and Its Impact on Children's Progress **5**
EUNSUK KIM

Perceptions of Educators Using Job Coaching to Increase Workplace Social Skills for Individuals with Intellectual Disability **22**
HEATHER M. DULAS and CARLY B. GILSON

How Parents' Expression of Their Meaningful Personal Projects Reflects Their Needs? **40**
LISE LACHANCE, SUZIE MCKINNON, LOUIS COURNOYER, and LOUIS RICHER

Putting Research into Practice: AAC Strategies for Children with Autism **63**
REBECCA ARCHER ANWAR and JULIET HART BARNETT

Feasibility of Interprofessional Education around Autism Spectrum Disorders **82**
ERIN ROTHERAM-FULLER, KASSANDRA SPURLOCK, MARIA DIXON, and NANCY SCHERER

Let Grow: Supporting Parents of Students with Intellectual Disability in Inclusive Higher Education Programs **98**
BETTY S. PATTEN, CLAIRE C. HEBERT, JESSICA H. MILTON, and CHRISTINE DREW

Evaluating Ohio's Postsecondary Programs for Students with Intellectual Disability: A Survey of Program Directors **114**
JESSIE C. GREEN, ANDREW BUCK, and MARGO IZZO

"You don't Know What You Don't Know": Intentionally Connecting Individuals with Autism and Law Enforcement Officers to Increase Safety **131**
MELISSA A. SRECKOVIC, CHRISTINE K. KENNEY, ALYSSA GOLDEN, RAY HALL, and HEATHER BROMLEY

Thinking Beyond the Classroom: Innovative Approaches to Amplify Voices of Students with Disabilities and Their Families **152**
LYNN M. SCOTT, ANNETTE ROMUALDO, JULIANA HIRN, and CHRISTINE PARSONS

Shifting Perspectives on Disability: Family Reflections on a Life Fully Lived with Down Syndrome **166**
TAMMY BACHRACH and MINA CHUN

Using the *Teach Your Child to Read in 100 Easy Lessons* Curriculum with a Child with Autism Spectrum Disorder **184**
SANDRA C. YEPEZ HARO, JENNIFER NINCI, and GREGORY G. TAYLOR

Research Informed Practice in Autism, Intellectual Disability, and Developmental Disabilities

Stanley H. Zucker, Jessica Matus, and Jesse Fleming
Arizona State University

Elizabeth Harkins
William Patterson University

On January 17 – 19, 2024, the Council for Exceptional Children Division on Autism and Developmental Disabilities (DADD) sponsored its Twenty-fifth International Conference: Research Informed Practice in Autism, Intellectual Disability and Developmental Disabilities. The conference was held at the Hilton Hawaiian Village Beach Resort. The DADD Board of Directors decided to devote this issue of the *DADD Online Journal* to conference papers. The conference brought together educators from school and college classrooms from all over the world. The conference included pre-conference training institutes and strands on assistive and adaptive technology, autism spectrum disorder, intellectual disability, mental health, paraprofessionals, parental engagement, post-secondary transitions, multiple disabilities and applied behavior analysis. The conference provided many parents, teacher educators, researchers, teachers, and other practitioners an opportunity to gather to learn the most current information related to providing services for individuals with autism, intellectual disability, and developmental disabilities.

This issue of the *DADD Online Journal* can enable those who attended the conference to see expanded papers, prepared by presenters, and also give those who were unable to attend an opportunity to benefit from the thoughtful work done by conference participants. Presenters were asked to submit papers based on their conference presentations. Papers submitted went under a blind review process by the Guest Reviewers who selected the papers for publication. We think the selection of papers represents an interesting assortment of topics and formats ranging from discussion papers to data based research to descriptions of classroom techniques. The papers selected do not necessarily represent all the topics covered at the conference but they do give a good idea of the variety and quality of the presentations. We would like to thank those authors who submitted papers for their efforts in making this issue of the *DADD Online Journal* possible.

In the first article, “Empowering Partnership: Parental Perspectives of Parent-Teacher Engagement in IEP Processes and Its Impact on Children’s Progress,” Eunsuk Kim uses phenomenological interviews and a survey to explore parent perspectives and experiences with Individualized Education Plan (IEP) processes. Specifically, the author investigated how parent engagement and experiences differed for parents above and below the median national average income in the U.S. Findings suggest that parents with higher incomes faced fewer challenges in communication and collaboration with teachers, which led to improved academic and social-emotional outcomes for their children. In contrast, parents with lower incomes desired higher-quality services, communication, and support. The author recommends that practitioners and service providers ensure all parents receive regular and clear communication as well as opportunities for collaboration with teachers and other professionals.

The next article, "Perceptions of Educators Using Job Coaching to Increase Workplace Social Skills for Individuals with Intellectual Disability," explored the perspectives of 173 educators serving as job coaches for students with disabilities transitioning into employment. Heather M. Dulas and Carly B. Gilson found that educators generally value the importance of job coaching and feel confident in their abilities, while their ratings of student independence in employment and social skills indicated areas for growth. The discrepancy between their perceived competence and student independence highlights the need for further research and training on evidence-based transition practices.

Personal projects are often driven by an individual's values, motivations, and priorities, significantly impacting their well-being, achievement, and satisfaction. In the article titled "How Parents' Expression of Their Meaningful Personal Projects Reflects Their Needs?," Lise Lachance, Suzie McKinnon, Louis Cournoyer, and Louis Richer utilized content analysis to examine how parents of individuals with intellectual disabilities describe and prioritize their personal projects. The study aimed to gain a deeper understanding of these parents' needs, priorities, and aspirations. Results indicated that parents engaged in or planned to engage in a variety of personal projects, generally discussing them in a positive light. However, they also identified challenges and barriers that hindered the pursuit of these projects. The researchers recommend that additional supports and services be provided to help parents overcome these obstacles, maintain their commitment to their goals, and successfully realize their personal projects.

In "Putting Research into Practice: AAC Strategies for Children with Autism," Rebecca Archer Anwar and Juliet E. Hart Barnett highlight that children with autism often face significant communication challenges, with 25-35% remaining minimally verbal despite early intervention efforts. They propose augmentative and alternative communication (AAC) as a potential support tool to enhance communication. However, challenges such as inadequate training and support can hinder effective AAC implementation. They reviewed and provided actionable tips for several evidence-based strategies for educators, including using multiple AAC modalities in the classroom, aided language modeling, and supportive communication partner behaviors. They emphasize collaboration between educators and speech-language pathologists to incorporate these strategies into daily routines, establish clear goals, and ensure consistent application, thereby enhancing communication skills and classroom engagement.

Erin Rotheram-Fuller, Kassandra Spurlock, Maria Dixon, and Nancy Scherer describe the need for professionals who work with students with disabilities, particularly students with autism, to collaborate effectively. In their article, "Feasibility of Interprofessional Education around Autism Spectrum Disorders," they introduce an interprofessional education (IPE) program that was developed between special education and speech-language pathologist students at the master's level. Program components included opportunities to learn from experts in the field and complete collaborative assignments, courses, and field experiences grounded in evidence-based practices. Program data and feedback from participants suggest that the program is feasible and effective. The authors conclude the article by advocating for additional interdisciplinary collaboration opportunities within professional training programs.

In the next article, "Let Grow: Supporting Parents of Students with Intellectual Disabilities in Inclusive Higher Education Programs," Betty Patten, Claire Hebert, Jessica Milton, and Christine Drew outline six intervention strategies designed to enhance communication and collaboration with families within inclusive postsecondary education (IPSE) programs. The authors present both system-centered approaches, which ensure consistent and streamlined communication with parents/guardians, and person-centered approaches, which address the unique experiences and needs of each student in the IPSE program. These strategies aim to create a more supportive environment that fosters student achievement and family involvement. Other ISPE programs may consider implementing these interventions to improve collaboration with families while continuing to promote student autonomy and success.

In “Evaluating Ohio’s Postsecondary Programs for Students with Intellectual Disability: A Survey of Program Directors,” Jessie C. Green, Andrew Buck, and Margo Izzo reported results from a survey conducted by Ohio’s Statewide Consortium (OSC). The survey gathered information on the current practice and future plans to implement standards and quality indicators in inclusive postsecondary education programs in Ohio for students with intellectual disability. It examined the alignment of these programs with the Think College Standards for Inclusive Higher Education (TCSIHE). Program directors at five institutions were surveyed, revealing strengths in campus access and trained staff, along with areas needing improvement. The OSC was noted as a positive influence on communication and collaboration. The authors highlight successful practices but also acknowledge limitations such as a small sample size and the absence of TCSIHE standards for consortiums. They recommend ongoing program evaluation, knowledge sharing, and further research to establish benchmarks for high-quality consortiums.

The next article, “You don’t Know What You Don’t Know”: Intentionally Connecting Individuals with Autism and Law Enforcement Officers to Increase Safety,” reported by Melissa A. Sreckovic, Christine K. Kenney, Alyssa Golden, Ray Hall, and Heather Bromley discuss the vital need to increase the safety of autistic individuals when they interact with law enforcement officers (LEOs). Previous research focuses on training effectives of increasing officer knowledge about autism, but there is a need for relationship-building between the two groups outside of crisis intervention. The authors implemented a relationship-building event between LEOs and autistic individuals and their families, and measured the perspectives of LEOs, volunteers, and community members who attended the event. Results emphasized the importance of relationship-building, inclusion, and issued a call to action for LEOs to increase the safety of individuals with autism in the communities in which they live.

In the article, “Thinking Beyond the Classroom: Innovative Approaches to Amplify Voices of Students with Disabilities and Their Families,” authors Lynn M. Scott, Annette Romualdo, Juliana Hirn, and Christine Parsons recognize that families are at the center of a child's development and education, and that strong partnerships between families and educators best support the child's learning and well-being. The authors considered an experiential, reflective approach to prepare teachers to operate from family-centered and trauma-informed perspectives, while acknowledging that caregivers face innumerable hurdles to accessing a complex and multifaceted special education system. Creating systems of familial involvement in the educational process necessitates embedding collaborative and reflective learning alongside a critical analysis of attitudes, beliefs, and actions concerning disability and inclusivity. Ultimately, the authors issued a call to action to value all voices in the education process.

In "Shifting Perspectives on Disability: Family Reflections on a Life Fully Lived with Down Syndrome," Tammy Bachrach and Mina Chun, explore the impact on family lives by their relationship with a family member with Down syndrome. The case study focuses on Joseph, born in 1961, and examines the evolving perspectives of his family from his birth to his passing in 2021. The authors illustrate transformations in the family's understanding of disabilities over decades, demonstrating a shift from deficit-based views and institutionalization to a focus on inclusion and individual potential. Initially perceived with pity, Joseph's life, enriched by his family's support and changing societal attitudes, highlights his remarkable emotional intelligence and positive impact on his family. The authors emphasize the importance of inclusive practices and the positive outcomes of strong family relationships, ultimately providing a counter-narrative to the prevailing stereotypes and underscoring the importance of recognizing individuals with disabilities for their unique contributions and relational identities.

Research shows that using direct instruction and errorless teaching or learning combined with an effective reading intervention (e.g., phonemic awareness, phonics, vocabulary, reading fluency, and reading comprehension), is effective for autistic children. In the final article, Sandra C. Yepez Haro, Jennifer Ninci and Gregory G. Taylor in their article, "Using the Teach Your Child to Read in 100 Easy Lessons Curriculum with a Child with Autism Spectrum Disorder" studied the *Teach Your Child to Read in 100 Easy Lessons* (TYCTR) curriculum to determine the effectiveness of TYCTR in the acquisition of oral reading fluency. They found emerging evidence for success in improving fundamental reading outcomes using this curriculum.

The conference provided educators and researchers with the opportunity to explore current research, topical issues, and best practices relating to autism, intellectual disability, and development disabilities. We hope readers of this research to practice issue of the *DADD Online Journal* find the information valuable and timely.

Correspondence concerning this article should be addressed to Stanley H. Zucker, Special Education Program, Mary Lou Fulton Teachers College, Box 871811, Arizona State University, Tempe, AZ 85287-1811. Email: stan@asu.edu

Empowering Partnership: Parental Perspectives of Parent-Teacher Engagement in IEP Processes and Its Impact on Children's Progress

Eunsuk Kim
University of Massachusetts Boston

Abstract: This study delves into parents' perspectives on parent-teacher engagement through an embedded case study employing phenomenological interviews and a brief survey. The overarching themes were identified across all parents (n=8), allowing for further examination of two distinct groups: parents with incomes below the average national median (70,784 a year; n=4) and parents with incomes above the average national median (n=4). Focusing on communication and collaboration with teachers and the Individualized Education Plan (IEP) team, and its impact on the development of children with disabilities (PreK-2nd), three key themes emerged: communication, special education services, and children's development. Notably, parents, irrespective of income, express a common desire for effective communication and collaboration to tailor their child's IEP appropriately. Findings reveal that parents with incomes below the national median (SES 1) perceived overall engagement with teachers and the IEP team negatively, citing delays in receiving special education services and a perceived impact on their children's social, emotional, and academic development. In contrast, parents with incomes above the national median (SES 2) reported positive relationships with teachers and the IEP team, highlighting timely and beneficial services that positively influenced children's learning, social, and emotional skills.

Parent-teacher engagement can be defined in many ways. Engagement consists of both communication and collaboration (Santiago et al., 2016). These two essential skills are necessary to maintain positive reciprocal relationships between parents and teachers and lead to children's growth and development (Park & Holloway, 2013). Collaboration between teachers and parents is particularly influential in the context of young children with disabilities, shaping their social, emotional, and cognitive development (Murray et al., 2018). Challenges arise when parents, especially those raising children with disabilities, report limited opportunities for active participation in the Individualized Education Plan (IEP) process, often being relegated to a passive role of listening without adequate time to address their concerns or questions (Reimen et al., 2010).

When working with parents from different socioeconomic statuses (SES), research has revealed that children with disabilities, whose parents maintained positive engagement with their children's teachers and related early childhood professionals, show positive skills and traits, such as motivation, ability to work with others, ability to focus on their work, social and emotional maturity, self-regulation, and self-esteem (Zulauf-McCurdy & Loomis, 2023).

Research underscores a significant link between IEP satisfaction and equitable parent-teacher engagement, challenging the misconception that higher SES parents inherently contribute more resources and involvement in their children's education (Sengönül, 2022; Slade et al., 2018). Contrary to stereotypes, higher SES parents may face fewer challenges in providing resources for academic and support services recommended during IEP meetings, including essential health care support (Fingerman et al., 2015). Another misconception is the assumption that parents facing financial challenges are less inclined to be involved in their children's learning (Gay et al., 2020). However, research demonstrates that parents across all SES levels actively seek to support their children through communication and collaboration with school professionals (Epstein, 2010). This challenges biases and underscores the imperative of recognizing and fostering parental engagement beyond economic backgrounds, promoting an equitable approach to educational involvement.

Collaborative practices that build relationships between parents, teachers, and related service providers contribute to achieving mutually agreed-upon outcomes and goals, fostering family competencies, and supporting child development (Division for Early Childhood Recommended Practices, 2014). These skills lay the foundation for high-quality early childhood education and enable parents and teachers to establish strong engagement, promoting children's growth and fostering trusting relationships (Adam et al., 2016; Dereli & Kurtca, 2022).

Purpose of the Study

The objective of this study was to investigate the variations in parent-teacher engagement, encompassing aspects like communication, collaboration, and the receipt of special education services, among parent groups with above and below-median national average income levels during the IEP process. The national average median income in the U.S. during 2021 was $70,784. This was based on collected information from 2022 according to the United States Census Bureau (Semega & Kollar, 2021). More specifically, the study aimed to explore the lived experiences of family members involved in the IEP process and to analyze the differences in experiences between these two parental groups. The overarching goal of this research is to provide insights that can guide other researchers and practitioners in their interactions and engagement with parents of children with disabilities within the IEP process.

Research Questions

The following are three central research questions that are important for this study and help the researcher and the audience evaluate the study:

1. What are the lived experiences of families communicating and collaborating with teachers and specialists through the IEP process?
   1.1. How do families perceive their interactions with teachers and specialists impacting their child's learning and development?
2. How do different SES groups' communication and collaboration with teachers and IEP team members differ from one another?
3.

Theoretical Framework

This study adopts Bronfenbrenner's Systems Theory (EST) as its central theoretical framework. Bronfenbrenner's theory views development as a complex interplay of relationships influenced by multiple levels of environment, encompassing home and school environments, cultural values, ethics, and more (Bronfenbrenner, 2005). The focus of this research is on the parents' experiences within the dynamic context of parent-teacher interactions and the broader implications of these experiences on children's learning and development.

Given the emphasis on parents' lived experiences and the specific relevance of the mesosystem to the research questions, the researcher chose to concentrate on this particular layer within Bronfenbrenner's EST. By delving into the mesosystem, the researcher aims to comprehend and compare various parent-teacher engagement dynamics within two distinct SES groups. This approach allows for an exploration of how these differing experiences in parent-teacher engagement impact children's overall development (Crawford, 2020).

By utilizing the mesosystem as a guiding layer, the researcher gains valuable insights into understanding parent-teacher interactions within the specific context of two SES groups. This lens helps in exploring the nuanced dynamics of parent-teacher engagement and its effects on early childhood learning and development within the chosen SES contexts.

Methodology

In exploring the lived experiences of parents engaged in the IEP process, the researcher deemed a qualitative research approach most suitable for capturing the nuanced views, perspectives, and ideas of the participants. Given the focus on parents from varying SES backgrounds, the researcher selected an embedded case study design, enabling an in-depth exploration of real-life contexts and allowing for sub-analyses that illuminate differing parental experiences related to SES through the IEP process (Yin, 2018). Refer to Figure 1 for an illustration of the study design.

To delve into the rich and detailed descriptions of participants' lived experiences, the phenomenological interview method was chosen as the primary data collection approach (Creswell & Poth, 2017). While traditionally associated with phenomenology, the phenomenological interview's adaptability makes it suitable for use within an embedded case study design. This method facilitates an exploration of both overarching parental experiences and the nuances within sub-groups, aligning with the research objectives.

Participants

Participants were selected based on their income level and then grouped according to their income level, using the national average median income of $70,784 as a criterion for categorization. The study comprised two groups: parents with incomes below the average median and parents with incomes above the average median. Eight participants, four from each income category, were chosen for the study. The selection aimed to provide a diverse representation of experiences related to SES in the context of the IEP process.

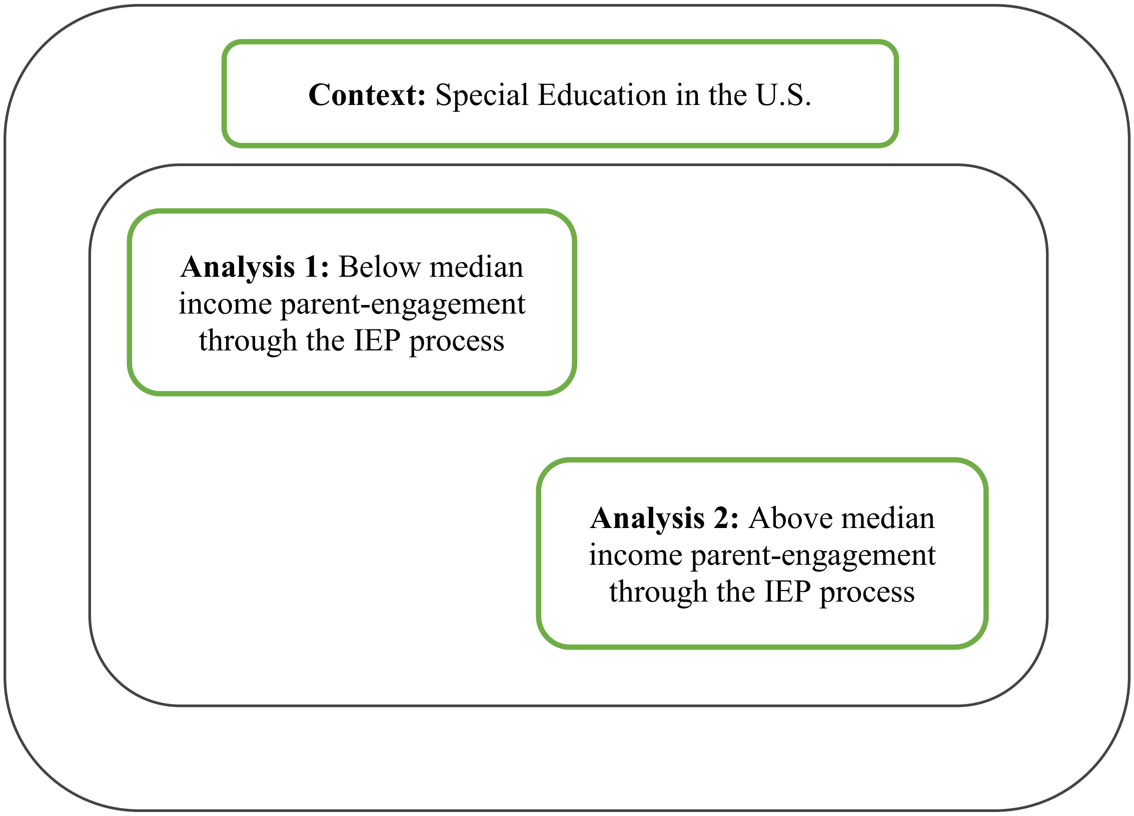
The study included a total of six female and two male participants, aged between 23 and 54 years. All participants demonstrated proficiency in English. Each participant was raising a child with a disability, and all children had IEPs in place. Additionally, the participants were evenly distributed between those who have their children enrolled in public schools and those who have their children enrolled in charter schools.

This research holds significance as it sheds light on the interactions between professionals and parents from different SES groups, emphasizing the potential impact on children with disabilities. Establishing reciprocal partnerships across families, schools, and teachers is crucial for making positive differences in children's school learning and overall development (Poynton et al., 2018). This methodology and participant selection aim to provide a comprehensive understanding of the lived experiences of parents within the IEP process, offering valuable insights for educational professionals and policymakers. Table 1 provides detailed information about the participant demographics.

Instruments

This study employed two distinct instruments to gather data from the participants. Firstly, two custom-designed data collection tools were created exclusively for this research: a

Figure 1. *Embedded Case Study Design*



demographic survey for participant selection, followed by a semi-structured phenomenological interview protocol. The demographic survey aimed to extract key demographic information to facilitate the comparison of crucial categories such as age, gender, income, occupation, and more. Utilizing this demographic data enabled the researcher to successfully recruit participants from two different groups. The second instrument, a semi-structured interview, allowed for the collection of data concerning parents' engagement with teachers and the resultant impact on young children with disabilities.

The researcher utilized the instrument to gather in-depth data about parents' IEP experiences. The instrument covered three sections listed below to better understand the research study that the researcher is investigating.

1. Frequency of communication and collaboration between parents and teachers
2. How communication and collaboration contributed to their child receiving services and their learning development
3. Parents' overall experiences in terms of communication and collaboration to define the meaning of parent-teacher involvement

Table 1. *Demographic Information*

Participant	Participant Age, Gender	Child	Child's Age, Gender	Child's Disability Category	Occupation	Income	Dependent
Jenny	23, Female	Tommy	4, Male	Autism Spectrum Disorder (ASD)	Psychiatric technician/ Student	$30,000-$39,999	3
Julie	30, Female	Emma	6, Male	Global Developmental Delay	Preschool lead teacher	$30,000-$39,999	2
Kayla	37, Female	Kane	7, Male	ASD, Developmental Delay	Adjunct faculty/ Student	$50,000-$55,999	3
James	41, Male	Henry	7, Female	Speech and language	Software developer	$150,000-more	1
Harley	42, Female	Shane	6, Male	ASD	Hair stylist	$20,000-$29,999	2
Hannah	42, Female	Matt	7, Male	Attention Deficit Hyper Disorder (ADHD)	Chorister/ Church choir	$70,000-$79,999	3
Sherry	44, Female	Billy	7, Male	ADHD	Product developer	$150,000-more	2
Jack	54, Male	Jimmy	7, Male	ASD, Landau-Kleffner Syndrome (LKS)	Respiratory therapist/ Supervisor	$150,000-more	1

Participants responded to questions regarding their preferred communication methods, the frequency of their interactions with teachers and IEP members, the appropriateness of their children's special education services, the outcomes of their children's development, and the overall experiences of communicating and collaborating with teachers and IEP team members.

Data Analysis

To understand the phenomenon of parents' experiences in collaborating and communicating with teachers and IEP team members and its overall impact on young children with disabilities, the researcher initially organized responses based on distinct interview questions posed to each participant. Within these participant responses, significant examples and statements were color-coded and highlighted. Subsequently, these coded excerpts were grouped on an Excel spreadsheet to identify overarching themes that would contribute to addressing the research questions.

In the initial coding phase, the researcher identified 15 codes relevant to the themes and sub-themes of the research study. Following the creation of initial codes, the researcher revisited them for criteria soundness. To ensure robustness, the researcher sought feedback from three early childhood research professionals, leading to some codes being grouped to represent multiple instances from the data. Consequently, the researcher revisited the data and initial codes, adjusted code phrases, identified additional codes, and compiled the final set of codes.

During the analysis, three overarching themes and corresponding sub-themes emerged from the interview data, initial codes, and final codes. This process involved two levels of analysis. The first analysis adopted a holistic approach by examining the entire dataset collected for the study. The second analysis focused on comparing participants based on their SES differences, providing deeper insights into the variations within the data.

Criteria of Soundness

The soundness criteria for the study involved Member Checking through OneDrive access for verifying findings, Confirmability through code and theme reviews to reduce biases, and Credibility by supporting arguments with current research. Disconfirming evidence was sought through self-questioning and collaboration for alternative explanations. Validity ensured consistency via consent forms, participant rights, and uniform questions. Reliability was maintained through consistent procedures, uniform questions, and secure OneDrive storage.

Results

Results are segmented into three parts. In the examination of the overall case, the initial segment of each theme delves into the overarching construct, addressing shared interests and preferences among all parents in the study. The subsequent segment of each theme explores the sub-themes associated with all participants in the study. The concluding segment of each theme focuses on the embedded analysis of sub-groups, such as parents with income below the national median (SES 1) and parents with income above the national median (SES 2).

Perceptions on Communication: Parent-Teacher Interactions

The research identified prevalent themes among all parents in the study, highlighting a shared desire for effective communication and collaboration with teachers and special educators. Parents consistently expressed their preference for communication through emails, newsletters, and similar platforms. Face-to-face interactions were also favored, with parents indicating a preference for actively engaging with their child's teachers and special education professionals, providing valuable suggestions and guidance that could enhance interactions with children with disabilities.

> We talk about whether or not he's progressing towards his goals, and what changes need to be made. I ask them questions and concerns and they consider all these

> seriously. They showed me all the data. And I think it's really effective.

Embedded Cases: Parent-Teacher Interactions (SES 1)

The research findings indicate that a significant number of parents from SES 1 reported encountering challenges in communication and collaboration with teachers and IEP team members. These participants expressed dissatisfaction with limited interactions and observed reduced engagement from teachers. Specifically, Jenny highlighted her perception of not being heard by teachers and IEP team members frequently, expressing disappointment in the perceived lack of empathy from these professionals during the interview.

> I feel like this year this schoolteacher, she's not as friendly as last year's teacher [sic]. I feel like she also doesn't communicate as well with me about Tommy. I feel like Tommy's teacher from last year was just overall more understanding, especially like on the autism spectrum.

Embedded Case: Parent-Teacher Interactions (SES 2)

The majority of parents from SES 2 reported positive communication and collaboration experiences with teachers. They emphasized feeling heard within the school community, noting appropriate representation during IEP meetings and parent-teacher conferences. James, for instance, expressed satisfaction with consistent acknowledgment of his voice by teachers and professionals throughout his child's school year.

> They're phenomenal. They're awesome. So, I really don't have any improvements. And I'm a pretty vocal person. And I speak up when I see something that I think can be improved upon. They're amazing. Yeah. 100% represented and my voice has been heard a lot! They let me know when their things are going on, and they provide solutions.

Perceptions on Communication: Parent-IEP Team Interactions

Several common themes surfaced during the interviews regarding parent-IEP team interactions. Parents expressed a desire for support in scheduling IEP meetings and understanding the documentation associated with these meetings. They emphasized the importance of communicative and collaborative decision-making within their child's IEP team. Additionally, parents sought more frequent opportunities to voice their opinions before, during, and after IEP meetings. One parent stated, “I still feel like this is [an] important time for us to be working together seriously to get to know each other and support each other for our child’s learning.”

Embedded Case: Parent-IEP Team Interactions (SES 1)

Some parents from SES 1 noted that their voices were more acknowledged by special education teachers and related specialists than by their children's regular classroom teachers, including the IEP team and related special education specialists. Harley, for instance, expressed satisfaction with her interactions with her child's special education teacher and the IEP team. She found these interactions beneficial for addressing challenges and openly discussing various ways to support her child. Harley praised the special education teachers for carefully listening to her concerns and providing the necessary support for her child.

> We basically found a unicorn. She truly has a mental health background. She understands our concerns with ABA, and

> she made a conscious choice to keep up with our neuro-diverse-affirming speech pathologist to support our child. That's why we love the charter school because they're so communicative.

In contrast, some parents from the same group reported a lack of assistance in scheduling IEP meetings and understanding necessary documentation. Jenny, a mother of three, expressed dissatisfaction, stating that her child's special education teachers failed to provide sufficient information about the IEP and the associated process, leaving her confused. Jenny noted that her interactions with school professionals did not show improvement compared to previous years.

> It would be helpful if there could be more information about IEPs to make the whole process available for the parents more easily. When we were in the process of having our middle child's IEP set up and he had the evaluations, and there's the paperwork that comes back right with all of the findings. I actually have somebody in our life who is an educational lawyer, and he had offered to look over the results and stuff and give me some pointers for when meeting with the team, which was helpful, because that wasn't available, you know, outside or from the school.

Embedded Case: Parent-IEP Team Interactions (SES 2)

Parents from SES 2 expressed satisfaction with school professionals and specialists, citing effective communication, collaboration, and services that met both parental and children's needs. This support encompassed regular conferences to discuss children's strengths and progress, weekly emails, and ongoing communication to address parents' questions and concerns. Hannah, for example, felt comfortable discussing her child's needs and strategies with special education teachers and the IEP team. The teachers actively listened to her concerns, incorporated parental strategies into teaching practices, and reported positive learning progress to the child's parents. Hannah mentioned,

> We have a pre-conference to get to know each other before school starts and there's a conference to talk about the child's strengths and needs. No issues with them. They give us a call and talk about our child's learning and highlights. Yeah, so lots of interaction.

Perceptions on Special Education Services: Parent Advocacy

Study participants uniformly emphasized their desire for schools to foster collaboration by actively and cooperatively listening to parents while advocating for both parental and children's needs. Furthermore, parents stressed the importance of school professionals being attentive by fulfilling requested resources and services, as well as taking into consideration parental concerns and input during the IEP.

> That was one of the problems and it took a few years for us to get all of that documentations for them to really see and understand that she was more at a 2.6-year-old rather than the age that she is physically.

Embedded Case: Parent Advocacy (SES 1)

Parents from SES 1 believed their children were receiving services but felt these services were inadequate for their needs. Consequently, they actively advocated for appropriate services during IEP meetings and other conferences, often persisting for months to years. Harley, dissatisfied with public school special education services, expressed a need to fight for the necessary support for her child. Both Harley and her children experienced frustration with the outcome. Harley said,

> That was pretty regular actually. So I had to fight for services. They first offered me, I want to say, like 45 minutes of combined services; it was a joke. They were much more focused on like, him hanging his coat up on the hook, and him putting his books in his book bag. I'm not saying that those things aren't important, but that was definitely not what he wants to learn, like he doesn't just care where his bookbag is in the classroom.

Kayla, a parent from SES 1 and an early childhood specialist, shared unique experiences. Her knowledge of both her rights as a parent and her child's rights in special education empowered her to advocate effectively for her child's needs. This proactive stance led to successful requests for services, with her voice being clearly heard by her child's special education teachers and the IEP team. Kayla's awareness of these rights not only benefited her child but also contributed to her recognition within the school community. Kayla said,

> I think my voice gets heard a lot in our school system. I am an early childhood specialist. So, I know a lot about kind of my rights as a parent, my kid's rights as a child with IEPs. So, my voice gets heard pretty loudly at these meetings.

Embedded Case: Parent Advocacy (SES 2)

Parents from SES 2 reported that their requests are consistently acknowledged by the IEP team. They expressed satisfaction with the services provided by special education teachers, finding them appropriate for their children. During IEP meetings, these professionals are communicative and willing to offer the necessary educational support and services. Overall, parents in this group are content with the collaborative efforts of the IEP team in providing suitable services for their children. Jack specifically mentioned that his child received daily learning support and requested services, contributing to meeting his child's needs. Jack said,

> So no, I really didn't have a whole lot of issues with the teachers and IEP teachers. They were pretty open and communicative. And we've been very collaborative. It is another good word. But you know, I think it was good and my son usually receives services that are appropriate for him.

Perception on Special Education Services: Appropriateness of the Special Education Services and Support

The study findings indicate a unanimous desire among parents for child-centered special education services and support both within and outside of school. Parents value teachers who exhibit welcoming behaviors in their interactions with students and families. The consensus from all parents in the study is a preference for teachers who demonstrate commitment and active engagement in supporting students' overall learning and needs. This includes incorporating various learning strategies suggested by parents and implementing diverse curriculums to effectively engage with students.

> The behavior team, they're there with him, you know, several hours a day. And they take notes, and they evaluate and, you know engage more with my child. I think the behavior team is understanding and helping my child a lot.

Embedded Case: Appropriateness of the Special Education Services and Support (SES 1)

Parents from SES 1 expressed that their children did receive special education services. However, they noted that the quality of these services was not as effective as desired. These parents conveyed frustration with the provided services, citing unsuccessful interventions and a lack of appropriateness for their children's needs. For instance, Julie mentioned that her child received Applied Behavior Analysis (ABA) but found it ineffective. Consequently, she had to incur additional expenses for private specialists to ensure her child received the necessary support and services. Julie explained,

> My child's school offered ABA, but it did not help my child and we felt frustration. I pulled him from ABA and kind of swore it off and we just hired a neuro-diverse affirming speech pathologist paid out of pocket.

Embedded Case: Appropriateness of the Special Education Services and Support (SES 2)

Parents from SES 2 reported effective child-oriented special education services both in and out of school. They noted increased interest in learning, hospitable behaviors from teachers, and active support for overall needs. Teachers incorporated diverse strategies, resulting in age-appropriate skill development. Sherry mentioned her child's successful progress in meeting learning goals set by the parent and the IEP team.

> I don't think Billy would be as far as he is without the constant and the frequent interaction between his teachers and us, and the IEP teacher, his special education teacher, and administration at the school. So all the interactions and supports have definitely led to him being probably two steps ahead of where, you know, he would have been at some other school.

Perceptions on Their Child's Development: Academic Development

Parents in the study emphasize the importance of tailored educational services for their children, aiming for academic and developmental milestones. They desire lessons aligned with their children's specific learning needs and interests, fostering an enjoyable learning experience. The manifestation of these expectations varies among groups, with a common concern that inadequate services lead to boredom and diminished interest in school curriculums.

> I feel like teachers this year do not support my daughter's education. My daughter came home one day and she was not happy. I asked her what happened and she said she does not enjoy learning and she feels like school activities are boring.

Embedded Case: Academic Development (SES 1)

Parents from SES 1 noted that special education accommodations had minimal impact on their children's learning. These parents reported that their children could effectively follow directions and perform well in in-class exams. For instance, Kayla shared that her child showed no learning challenges and performed adequately in various subjects. However, she expressed concerns about the adequacy of special education support for her child's academic growth in reading, writing, and science. Kayla said, “His reading and writing and concepts like science have not really impacted him. He is doing really well with all of that.”

Other parents conveyed dissatisfaction with the lack of child-centered support and services tailored to their children's learning needs. They felt that their children were receiving education unsuitable for them, focusing solely on standard age-group milestones rather than individual learning and developmental levels. For instance, Julie expressed disappointment that her first-grade child wasn't receiving suitable education in class, leading to frustration and a disinterest in learning.

> Instead of having a first grader learning how to read, my daughter is still learning the basics of noticing the letters in her name, noticing which letter is which letter. They kept trying to push more difficult abilities for her to do, trying to keep her with her surrounding peers.

Embedded Case: Academic Development (SES 2)

The majority of parents from SES 2 noted enhanced academic learning and positive learning behaviors in their children. They appreciated the school's methodology and its interactive engagement. For instance, Jack observed positive changes in his child's academic learning and social interactions since receiving special education support. Previously facing challenges in daily activities and interactions, Jack's son showed notable improvement after the school's intervention.

> His learning was much better. He was able to do his daily activities. A big thing was prior to this, it was tough to take him out in public. It was tough to take him to a grocery store. We couldn't really sit with him at a restaurant. Once he was there, he had that day-to-day, repetitive over and over again, and that's how Jimmy learned. It was repetition, practice, practice, practice.

Perceptions on Their Child’s Development: Social Development

Parents in the study unanimously expressed a shared desire for their children to participate in positive social interactions with both classroom and special education teachers as well as classmates. They emphasized the importance of developing social skills through inclusive learning experiences and social activities in the classroom setting. One parent said, “It is hard for him to find new friends. At least at this school, we want, like our child to make new friends and build relationships with their teachers and other people in his life.”

Embedded Case: Social Development (SES 1)

Parents from SES 1 expressed concerns about their children's social skills, perceiving a lack of improvement or support throughout the school year. They attributed this to teachers who are either new to the system or insufficiently trained to assist children requiring extra support. Some parents reported morning motivation challenges, as their children were reluctant to return to school due to a perceived absence of friends and supportive teachers. Jenny said,

> And I think it really kind of traumatized him. Because now we still have days where we fight to get him to school. He thinks he doesn't have any friends and this makes me really upset, although we are doing work to kind of fix that now.

Embedded Case: Social Development (SES 2)

Parents from SES 2 reported positive social development in their children. These children enjoyed interacting with teachers and peers through hands-on learning activities, fostering a keen interest in school. Parents noted their children's enthusiasm for sharing daily activities and interactions. Teachers played a proactive role in supporting social interactions, addressing feelings of isolation, and facilitating friendships. For example, Hannah highlighted her child's challenges in socializing, but with the dedicated support of teachers and a structured approach to social skill development, the child successfully made friends and exhibited positive social interactions.

> My 7-year-old, he starts getting along with his peers and teachers are helping him make new friends. He's excited to see his teachers and friends. He talks about positive things after school. He is excited to go back to school and spend time with his peers and teachers.

Perceptions on Their Child's Development: Emotional Development

Parents in the study seek positive emotional responses from their children's learning experiences, desiring happiness, motivation, and a willingness to learn. They emphasize the importance of teachers providing appropriate, child-centered opportunities to build skills and confidence. Parents believe that focusing on children's strengths and interests, along with words of encouragement, can enhance emotional attitudes toward learning. They stress that fostering confidence and motivation is crucial to sustaining children's interest in school. One parent stated, "Phenomenal, good, real good. Yeah, my child is engaged and he is happy with his new teachers."

Embedded Case: Emotional Development (SES 1)

The majority of the parents from SES 1 expressed concerns about their children's emotional development. One exception was a parent with a child in a charter school, reporting positive emotional responses. In general, children faced challenges understanding and managing their individual emotional needs, leading to stress and emotional breakdowns. Kayla shared that her child started disliking school and teachers due to a lack of understanding and support, causing significant stress and reluctance to attend school.

> He was pushing himself so hard to not cause issues in the classroom, and to hold in like a lot of big emotions. He was coming home and disintegrating, like, having a huge outburst. And it's like it was just miserable.

Embedded Case: Emotional Development (SES 2)

Parents from SES 2 reported a correlation between their children's academic improvement and positive emotional responses. With support from special education teachers, children gained independence in tasks, leading to expressions of joy, happiness, and a desire to share progress with parents. James highlighted how his child displayed increased positive emotions after each session with the special education teacher.

> So, he receives speech therapy with Miss Jodi, who's the IEP teacher. He's excited to see her. He talks positive things after he's had a session with her. And she sent us a few nice, real nice emails about him. And you can really see him working on his articulation, you know, in some of his letter sounds that he struggles with and he is really happy about his progress.

Discussion

Establishing positive teacher-parent relationships is crucial for supporting students with disabilities, irrespective of SES differences (Redding et al., 2011). Strong engagement fosters mutual understanding and effective learning strategies, particularly in early childhood settings (Baker et al., 2016). Rooted in Bronfenbrenner's ecological perspective, this study explores diverse outcomes for parents from varying SES backgrounds in IEP contexts, offering a unique perspective compared to existing literature on parent-teacher engagement in traditional school settings. Examining the engagement experiences of parents from different SES groups sheds light on challenges encountered during the IEP process.

Parents from SES 2 faced fewer challenges in communication and collaboration with teachers, resulting in positive academic and socio-emotional outcomes for their children. In contrast, parents from SES 1 sought increased social interactions, information, and advocacy for higher-quality special education services. They voiced concerns about inadequate educational support and a sense of exclusion from their child's support team due to communication gaps (Mereoiu et al., 2016; Podvey et al., 2013; Welchons & McIntyre, 2015). Recognizing these disparities can empower educators to develop equity-oriented strategies for positive communication and collaboration, leveraging the strengths of both parents and children to establish inclusive partnerships and promote holistic development (Kambouri et al., 2022).

While the chosen participants may not represent all parents of children with disabilities, exploring the experiences of two SES groups provides valuable insights into challenges faced in collaborating with school special education service providers. Understanding this demographic information and parents' IEP experiences broadens the study's scope, allowing for exploration of additional facets of family-school engagement, specifically focusing on income disparities. By investigating SES differences, the researcher aims to identify innovative strategies to address and mitigate challenges in teacher-parent relationships.

Implications for Practice

Drawing from real-world challenges, educators and practitioners can strategize ways to conduct IEP meetings within a family-oriented, inclusive environment, fostering effective communication and collaboration with parents. This section aims to explore challenges that may arise during IEP meetings and propose three scenarios for practitioners to consider, supporting positive parent-teacher engagement. These strategies can prove beneficial for teachers aiming to enhance collaboration with parents.

One challenge is the constraint of time during IEP meetings, potentially leaving parents feeling rushed and undervalued. Interruptions or restrictions on parents sharing their insights can lead to a sense of overwhelm and diminished trust. To address this, practitioners can facilitate successful IEP meetings by allowing parents to take documents home beforehand for careful review, promoting a more thorough discussion during the meeting (Reiman et al., 2010).

When insufficient time during IEP meetings hinders comprehensive discussions, practitioners can offer post-IEP meetings in a stress-free environment. This allows parents and special education teachers to engage in discussions to incorporate changes and improvements to the IEP. Regular communication and collaboration, tailored to parents' preferences, become crucial during these post-IEP meetings, ensuring responsiveness to children's strengths and needs (Haines et al., 2015).

Throughout the year, parents may encounter difficulties maintaining communication with special education teachers, especially during situations like the COVID-19 pandemic. Practitioners can address this challenge by utilizing various online platforms for communication (Scheef et al., 2022). Online tools such as Google Classrooms and Classroom DoJo facilitate the delivery of up-to-date documents and resources, enabling parents to access regular updates about their children and pertinent information related to their IEPs. Moreover, offering IEP meetings through platforms like Zoom provides flexibility for parents with busy schedules or transportation limitations, ensuring their continued involvement in their children's IEP and overall communication with the school IEP team.

Implication for Research

To enhance our understanding of the dynamics between education professionals and parents, future research should delve into the behavioral and attitudinal variations exhibited by teachers and other school staff (Chaiklin, 2011). Notably, classroom teachers and special education teachers may manifest distinct behavior patterns towards parents, as discerned from the data analysis conducted in this study. While some educators display enthusiasm towards certain parents, others might not encounter these positive responses. In some instances, parents might even face judgment or shaming behaviors from school professionals. Therefore, a comprehensive examination of behaviors can yield more nuanced insights into educators' perspectives within contemporary school settings.

Understanding human attitudes is crucial, as they can be inferred from behaviors. Teachers may harbor different attitudes towards various individuals, including co-workers, parents, and students. While these attitudes should not hinder teacher-student and teacher-parent engagement, they can impact the extent of such interactions. Exploring educators' attitudes towards students and parents can be instrumental in devising intervention strategies to potentially enhance parent-teacher engagement and mitigate frustrations that teachers may experience when working with parents (Dor & Naidu, 2012).

Future research ought to scrutinize how income disparities and education levels influence engagement with teachers and related professionals. The conflation of income levels with educational levels, often due to proxy variables and varying definitions, poses a challenge. For instance, studies that overlook income levels may use educational attainment as a substitute for understanding household income. Ensuring transparency regarding income levels, if feasible, is essential to accurately represent parents in the school system. This approach could contribute to a more precise understanding of the impact of SES factors on parent-teacher engagement.

Conclusion

The study highlights the critical need for strengthened parent-teacher engagement to provide robust support for young children, necessitating a transformative mindset shift where both parties treat each other as equals and actively engage in learning opportunities to understand their collaborative roles better. Establishing mutual trust and respect is pivotal for the overall development of young children, with parents guiding and supporting teachers and related professionals, while teachers address parental concerns irrespective of differences in educational philosophy. Offering potential solutions that benefit all stakeholders fosters a collaborative environment.

Professionals who actively listen and advocate for their students and families can build trust, facilitating sustained positive engagement with parents and leading to the provision of appropriate special education services for children, ultimately aiding them in reaching their developmental milestones effectively.

References

Baker, T., Wise, J., Kelley, G., & Skiba, R. (2016). Identifying barriers, creating solutions to improving family engagement. *School Community Journal, 26*(2), 161–184. https://files.eric.ed.gov/fulltext/EJ1124003.pdf

Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development.* SAGE.

Chaiklin, H. (2011). Attitudes, behavior, and social practice. *The Journal of Sociology & Social Welfare, 38*(1), 31-54. https://doi.org/10.15453/0191-5096.3583

Crawford, M. (2020). Ecological systems theory: Exploring the development of the theoretical framework as conceived by Bronfenbrenner. *Journal of Pub Health Issues and Practices*, *4*(2), 170-175. https://doi.org/10.33790/jphip1100170

Creswell, J., & Poth, C. (2017). *Qualitative inquiry and research design: Choosing among five approaches*. SAGE.

Dereli, F., & Kurtca, T. T. (2022). Parent engagement in early childhood education: Pandemic period. *Southeast Asia Early Childhood Journal*, *11*(1), 35-48. https://doi.org/10.37134/saecj.vol11.1.3.2022

Division for Early Childhood of the Council for Exceptional Children. (2014). *DEC recommended practices*. https://divisionearlychildhood.egnyte.com/dl/7urLPWCt5U/?

Dor, A., & Naidu, T. B. R. (2012). Teachers' attitudes toward parents' involvement in school: Comparing teachers in the USA and Israel. *Issues in Educational Research, 22*(3), 246-262. https://www.researchgate.net/publication/288150009

Epstein, J. L. (2010). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappa International*, *92*(3), 81-96. https://doi.org/10.1177/003172171009200

Fingerman, K. L., Kim, K., Davis, E. M., Furstenberg, F. F., J.r, Birditt, K. S., & Zarit, S. H. (2015). I'll give you the world: Socioeconomic differences in parental support of adult children. *Journal of Marriage and the Family*, *77*(4), 844–865. https://doi.org/10.1111/jomf.12204

Gay, B., Sonnenschein, S., Sun, S., & Baker, L. (2020). Poverty, parent involvement, and child's reading skills: Testing the compensatory effect of the amount of classroom reading instruction. *Early Education and Development*, *32*(9), 1-13. https://doi.org/10.1080/10409289.2020.1829292

Haines, S. J., Gross, J. M. S., Blue-Banning, M., Francis, G. L., & Turnbull, A. P. (2015). Fostering family-school and community-school partnerships in inclusive schools. *Research and Practice for Persons with Severe Disabilities*, *40*(3), 227-239. https://doi.org/10.1177/1540796915594141

Kambouri, M., Wilson, T., Pieridou, M., Quinn, S. F., & Liu, J. (2022). Making partnerships work: Proposing a model to support parent-practitioner partnerships in the early years. *Early Child Education Journal, 50*(4), 639-661. https://doi.org/10.1007/s10643-021-01181-6

Mereoiu, M., Abercrombie, S., & Murray, M. (2016). One step closer: Connecting parents and teachers for improved student outcomes. *Cogent Education*, *3*(1), 1-19. https://doi.org/10.1080/2331186X.2016.1243079

Murray, M., Munger, M. H., Colwell, W. B., & Claussen, A. J. (2018). Building capacity in special education: A statewide initiative to improve student outcomes through parent-teacher partnerships. *School Community Journal*, *28*(1), 91-105. https://files.eric.ed.gov/fulltext/EJ1184770.pdf

Park, S., & Holloway, S. D. (2013). No parent left behind: Predicting parental involvement in adolescents' education within a socio demo graphically diverse population. *The Journal of Educational Research*, *106*(2), 105-119. https://doi.org/10.1080/00220671.2012.667012.

Podvey, M. C., Hinojosa, J., & Koenig, K. P. (2013). Reconsidering insider status for families during the transition from early intervention to preschool special education. *Journal of Special Education*, *46*(4), 211-222. https://doi.org/10.1177/0022466911407074

Poynton, J., Kirkland, R., & Makela, C. (2018). Superintendents building public trust and engagement in five public school communities. *School Community Journal*, *28*(2), 263– 295. https://files.eric.ed.gov/fulltext/EJ1201954.pdf

Redding, S., Murphy, M., & Sheley, P. (2011). *Handbook on family and community engagement.* https://www.schoolcommunitynetwork.org/downloads/FACEHandbook.pdf

Reimen, J. W., Beck, L., Coppola, T., & Engiles, A. (2010). Parents' experiences with the IEP process: Considerations for improving practice. *CADRE* 1-9. https://files.eric.ed.gov/fulltext/ED512611.pdf

Santiago, R. T., Garbacz, S. A., Beattie, T., & Moore, C. L. (2016). Parent-teacher relationships in elementary school: An examination of parent-teacher trust. *Psychology in the Schools*, 53(10), 1003-1017. https://doi.org/10.1002/pits.21971

Scheef, A. R., Hollingshead, A., & Hayes, J. (2022). School personnel perceptions of video conference individualized education program meetings. *Journal of Special Education Technology*, *38*(2), 187-197. https://doi.org/10.1177/01626434221108888

Semega, J., & Kollar, M. (2021). *Income in the United States: 2021*. U.S Census Bureau. https://www.census.gov/library/publications/2022/demo/p60-276.html

Sengönül, T. (2022). A review of the relationship between parental involvement and children's academic achievement and the role of family socioeconomic status in this relationship. *Pegem Journal of Education and Instruction*, *12*(2), 32-57. https://doi.org/10.47750/pegegog.12.02.04

Slade, N., Eisenhower, A., Carter, A. S., & Blacher, J. (2018). Satisfaction with individualized education programs among parents of young children with ASD. *Exceptional Children*, *84*(3), 242-260. https://doi.org/10.1177

/0014 40 2917742923

Welchons, L. W., & McIntyre, L. L. (2015). The transition to kindergarten for children with and without disabilities: An investigation of parent and teacher concerns and involvement. *Topics in Early Childhood Special Education* , *35*(1), 52-62. https://doi.org/10.1177/0271121414523141

Yin, R. K. (2018). *Case study research and applications: Design and methods* (6th ed.). SAGE.

Zulauf-McCurdy, C. A., & Loomis, A. M. (2023). Parent and teacher perceptions of the parent-teacher relationship and child self-regulation in preschool: Variations by child race. *Early Childhood Education*, *51*(2), 765-779. https://doi.org/10.1007/s10643-022-01341-2

Correspondence concerning this article should be addressed to Eunsuk Kim, Department of Curriculum and Instruction (Early Childhood Education), University of Massachusetts Boston, Boston, MA. E-mail: Eunsuk.kim001@umb.edu

Perceptions of Educators Using Job Coaching to Increase Workplace Social Skills for Individuals with Intellectual Disability

Heather M. Dulas
University of Houston

Carly B. Gilson
The Ohio State University

Abstract: Adults with intellectual disability (ID) often have difficulty regulating their behavior in social settings including meeting the social demands of the workplace. In the secondary school setting, students with ID often receive employment skills instruction and support from job coaches. We conducted a survey of 173 educators serving in secondary settings on the use of job coaching as an intervention to increase workplace independence by focusing specifically on their perceptions of the job coaching role, the strategies they currently use, and the training needs they identify. We evaluated how perceptions differed by educator role, years of experience, and gender. Participants indicated student independence in the workplace is a highly valuable trait along with a need for increased demonstration of independence by their students in both employment skills and social skills. We share implications for future research and practice.

Obtaining a job is a common goal for young adults as they prepare to move forward following high school graduation. Work not only provides the opportunity to earn income, but also creates chances to develop relationships with new others, build supportive networks and contribute to the community (Young & Rooney, 2023). Engaging in meaningful employment is as essential to young adults with intellectual disability (ID) as it is to their peers (Meltzer et al., 2018; Trainor et al., 2020; Young & Rooney, 2023). Employment contributes to individuals' autonomy and independence including individuals with ID (Narayan et al., 2023). Individuals with disabilities value the opportunity to work, yet in 2023 only 22.5% of people with disabilities in the labor force were employed (Bureau of Labor Statistics, 2024). Although this represents the highest employment-population ratio ever recorded for individuals with disabilities since comparable data were first collected in 2008, the Bureau of Labor Statistics (2024) reports that of individuals with disabilities who did have jobs, 29% were working part time compared with 16% of individuals without disabilities.

Oftentimes, young adults with disabilities lack the work-related or social skills needed to find, obtain, and maintain employment (Carter et al., 2021; Young & Rooney, 2023). These deficiencies in employment-related social skills lead to unemployment with these students (Agran et al., 2016; Young & Rooney, 2023). Being proficient in social skills helps individuals adapt to and navigate the unpredictable aspects of working in the community (Cannella-Malone & Schaefer, 2017). Therefore, more training is needed to facilitate the transition to successful employment for individuals with disabilities. In a national survey, secondary educators (i.e., special education teachers, transition coordinators, and job coaches) indicated work-related social skills (e.g., notifying supervisor when assistance is needed, seeking clarification for unclear instructions responding appropriately to critical feedback) as crucial to successfully navigating the work environment (Agran et al., 2016). Agran and colleagues (2016) reported that employers value teaching social skills in secondary school settings where students can engage regularly with peers and staff to provide a predictable basis for practicing employment skills. In addition to school-based social skills instruction, young adults with ID benefit from practical experience in work environments (Kregel et al., 2020; Rooney-Kron & Dymond, 2021). Young and Rooney (2023) emphasize the importance of teaching social skills to obtain work experience along with the need to practice social skills within the work setting to prepare for successful outcomes in inclusive employment environments. The combination of instruction and practice in both school and work settings provides a broader variety of experiences incorporating social skills that can be transferred to future jobs.

In the secondary school setting, students with ID often receive employment skills instruction and support from job coaches (Brock et al., 2016; Hughes & Carter, 2012). Job coaches provide systematic instruction and proximal support in both school and community-based settings to foster employment skills and increase student independence on the job (Wehman et al., 2021; Wenzel et al., 2022). Instruction provided by job coaches typically includes using strategies such as task analysis, different levels of prompting, modeling, verbal instruction, and performance feedback to support students as they learn job responsibilities while using fading techniques to gradually reduce levels of support and increase independence (Gilson et al., 2021; Wenzel et al., 2022). Effective job coaching can have a positive impact on students' independence in the workplace and set them up for long-term success (Brock et al., 2016). Therefore, providing training in job coaching strategies and ongoing professional development is essential for educators serving in job coaching roles.

Even though job coaches are expected to provide support and instruction, they rarely receive specific training in how to implement systematic employment instruction (Gilson et al., 2017, 2021; Wenzel et al., 2022). Often paraeducators serve as job coaches for secondary students with disabilities in both school and community settings. Paraeducators commonly do not have access to preservice and in-service training opportunities (Douglas & Uitto, 2021; Mason et al., 2021). Additionally, paraeducators typically have minimal experience when beginning their roles and are trained in either large group settings or on-the-job as supervisors time permits (Mason et al., 2021). Thus, paraeducators need targeted in-service training to gain a knowledge base and develop the skills needed to support students and assist teachers (Douglas & Uitto, 2021; Mason et al., 2021). Without access to training and professional development, job coaches may have limited ability to effectively provide the employment skills instruction and support needed to facilitate student growth.

The need for equipping job coaches is echoed by teachers as well. In a recent study of teacher perceptions of barriers to providing work-based learning experiences (WBLEs), Rooney-Kron and Dymond (2021) reported the top barrier identified by educators was resources. Staff resources, including training of staff (i.e., job coaches, paraprofessionals) who support students in school and community-based settings were identified as a primary barrier to providing WBLEs. Teachers indicated a need for job coaches with specialized training to support students in the classroom and in the community; they also indicated reluctance to send staff out in the community because it led to short-staffing in classroom settings (Rooney-Kron & Dymond, 2021). Mason and colleagues (2021) used focus groups to examine the responsibilities and training needs of both paraprofessionals and the teachers who supervise them along with the factors that support or impede special educators' self-efficacy. Common themes that emerged among the paraprofessionals and teachers were lack of relevant training that is applicable to the students they serve along with a lack of time to communicate and collaborate as an educational team (Mason et al., 2021). These findings demonstrate the essential need to provide specialized training for educators who support transition-age students in developing employment skills in preparation for inclusive employment in the community.

Gilson and colleagues (2021) evaluated a pilot professional development program, the Job Coaching Academy (JCA), which was developed to help job coaches support their students to become more independent in the workplace both in terms of vocational skills and work-related social skills. During the pilot program using JCA training, 46 secondary educators across three school districts participated in one day training sessions in small groups in their home districts. The training was delivered during a six-hour in-service session with breaks and included content divided into three sections: (1) The Importance of Early Work Experiences and School-Based Preparation, (2) Establishing Sustainable Independence, and (3) Promoting Inclusive Workplaces (Gilson et al., 2021). Job coaches' views and coaching methods were measured using a pre/post training survey. Job coaches were also observed working with students to collect data on job coaching behaviors. Findings indicated participation in the JCA built educators' confidence in their skills related to job coaching and led to growth in their job coaching behaviors.

Outside of the JCA pilot study, there is no known comprehensive training program that focuses specifically on job coaches in high school and transition settings. The current study, an extension of the JCA pilot program (Gilson et al., 2021), will add to the research base by examining how job coaches outside of those participating in professional development sessions like those in the pilot study view their role as job coaches, what type of strategies they commonly implement with their students, and the extent to which they feel knowledgeable implementing the strategies.

Purpose of the Current Study

The purpose of this study was to examine the perceptions of educators related to their roles as job coaches. The following research questions were explored:

1. How do educators view their role as job coaches?
2. To what extent do educators feel knowledgeable implementing job coaching strategies to support their students with disabilities?
3. Do these perceptions vary by educator role, years of experience, and gender?

Method

Study Design

The present study used a survey to examine educators' perceptions related to their roles as job coaches and their experiences with training and implementing coaching strategies designed to increase vocational skills, especially employment-related social skills, of secondary students with disabilities. The survey measure was replicated from a pre/post measure developed by Gilson and colleagues (2021) to evaluate the efficacy of the pilot JCA training on shaping educator perceptions. The survey measure was created by reviewing extant literature surrounding professional development for transition educators (e.g., Morningstar & Benitez, 2013; Blanchett, 2001). Gilson and colleagues (2021) piloted an eight-item survey with transition educators across three school districts. The survey includes statements such as, "I feel knowledgeable about the best strategies to use in job coaching" and "Job coaching has a beneficial role in the workplace setting," which educators evaluated using a 5-point Likert-type scale (Gilson et al., 2021). The survey was updated with an additional question related to educators' level of comfort being referred to as job coaches. Cronbach's alpha for the survey items was .82, indicating a high rate of internal reliability.

In the present study, we used the measure to explore the similarities and differences between perspectives and practices of educators who use job coaching strategies to improve employment skills of secondary students with disabilities. In particular, we were interested in distributing the survey to a broader, more diverse sample to examine perceptions independent of their experiences with training or access to professional development.

Ethics

IRB approval was obtained prior to recruiting participants. Participants were recruited in person through a professional development series offered by the authors' university to a large urban district and online through special education service cooperative listservs in school districts located in Texas and social media research/teaching groups (i.e., National Association of Special Education teachers, Think College Program Staff, Special Education Teachers, Texas Special Education Teachers). Participants had the opportunity to ask questions about the study and informed consent was obtained via a Qualtrics survey link or on paper (for in-person participants).

Participants

Participants were 173 educators, primarily special education teachers (*n* = 88) or paraprofessionals (*n* = 69). Participants met the following criteria: (a) served during the 2021-2022 academic year as job coaches overseeing young adults ages 18-21 with disabilities; and (b) supported students to learn employment skills in either school or community-based employment settings. Participants responded from four states (i.e., Iowa, Minnesota, Missouri, Texas). The average age of educators was 31.9 years (*SD* = 8.4; range 18-65). The average number of years of experience was 6.5 years (*SD* = 5.1; range 0-32). Nearly all (90.8%) had up to ten years of experience in job coaching roles, including 55.5% who had 0-5 years of experience and 35.3% who had 6-10 years of experience. The educators reported their positions as special education teachers (52.4%), paraprofessionals (41.1%) and other roles (6.5%). Most educators (78.6%) were Black or African American, 12.7% were White, 2.9% were Asian/Pacific Islanders, 2.9% were Latino or Hispanic, 2.3% were Native American or Aleut, and 0.6% preferred not to answer. In terms of highest education, most participants (55.5%) reported having bachelor's degrees, 18.5% had graduate degrees, 13.3% had some college experience, 5.8% had associate degrees, and 6.9% had high school diplomas or the equivalent. Table 1 displays a summary of the Job Coach Demographics.

Measurement of Job Coaches' Perspectives

Gaining an understanding of educators' perspectives on job coaching experiences and strategies was essential to exploring our research questions. To capture this information, we used surveys to collect data from participants. Survey research is a useful

Table 1

Job Coach Demographics

Demographic	*N*	%
Age, *M* (SD)	31.9 (8.4)	
Years of experience, *M* (SD)	6.5 (5.1)	
0-5	96	55.5
6-10	61	35.3
11-15	8	4.6
16-20	1	0.6
21-25	1	0.6
26-30	1	0.6
31-35	1	0.6
Position Type		
Paraprofessional	69	41.1
Special education teacher	88	52.4
Other	11	6.5
Gender		
Male	121	69.9
Female	52	30.1
Other		
Racial/ethnic background		
Asian/Pacific Islanders	5	2.9
Black or African American (non-Hispanic)	136	78.6
Latino or Hispanic	5	2.9
Native American or Aleut	4	2.3
White or Caucasian (non-Hispanic)	22	12.7
Other	0	0
Prefer not to answer	1	0.6
Highest level of education completed		
High school or equivalent	12	6.9
Some college	23	13.3
2-year college degree	10	5.8
4-year college degree	96	55.5
Graduate degree	32	18.5

Note. One participant did not provide a response for the “Years of experience” variable. Five participants did not provide a response for the “Position Type” variable.

Table 2

Perspectives of Educators in Job Coaching Roles

Survey Item	% selecting each response					*M* (*SD*)
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
I am comfortable being referred to as a job coach.	0	4.0	11.0	65.3	19.7	4.01 (0.69)
I have been trained well on how to be a job coach.	2.3	4.0	11.0	43.9	38.7	4.13 (0.93)
I feel effective in my role as a job coach.	1.7	2.9	8.7	51.0	35.8	4.16 (0.83)
I feel knowledgeable about the best strategies to use in job coaching.	1.2	4.6	6.9	52.0	35.3	4.16 (0.83)
I think student/employee independence is an important part of job success.	1.7	1.0	4.6	54.3	38.2	4.25 (0.80)
I feel comfortable integrating specific employment skill strategies in the classroom.	0	2.3	4.6	42.8	50.3	4.41 (0.69)
Most of my students are independent in practicing employment skills.	1.0	6.4	11.6	45.7	35.8	4.10 (0.88)
I feel comfortable integrating specific social-skill training in the classroom.	1.2	1.7	4.0	49.7	43.4	4.32 (0.74)
Most of my students are independent in practicing social skills.	1.2	5.2	16.2	49.1	28.3	3.98 (0.87)

Note. Percentages are based on 173 participants.

method for gathering information about population groups to learn more about their characteristics, opinions, attitudes, and previous experiences (Leedy & Ormrod, 2005). Although researchers may not be able to survey an entire population of interest, information gathered from a sample of the population can provide an idea of the group's perceptions. We chose to use a survey to gather input from educators to address our research questions: (1) *How do educators view their role as job coaches?* (2) *To what extent do educators feel knowledgeable implementing job coaching strategies to support their students with disabilities?* and (3) *Do these perceptions vary by educator role, years of experience, and gender?*

Data Collection and Analysis

All participating educators completed a survey about their current perspectives and views related to their roles as job coaches. Surveys were available in both paper form and online via Qualtrics link. Data collection took place between November 2021 and April 2022. Five participants (3%) completed the survey in paper form and 168 participants (97%) completed the survey online. We used descriptive statistics (i.e., *M*, *SD*) to summarize all ratings by item related to each of our research questions. Analysis of Variance (ANOVA) was used to investigate whether ratings varied by educator role, years of experience, and gender.

Results

The goal of this study was to explore the perspectives of educators serving as job coaches for secondary students with disabilities to gain an understanding of how they view their role and to what extent they feel knowledgeable implementing job coaching strategies to support their students in gaining employment skills. We also wanted to explore whether ratings varied by educator role, years of experience, and gender. A nine-item survey was given to the educator participants (n = 173). Table 2 displays the percentage of educator participants selecting each response.

Perspectives on Job Coaching Role

The majority (85%) of educators selected "Agree" or "Strongly Agree" in response to "I am comfortable being referred to as a job coach"; 82.6% of educators selected "Agree" or "Strongly Agree" in response to "I have been trained well on how to be a job coach"; 86.7% of educators selected "Agree" or "Strongly Agree" in response to "I feel effective in my role as a job coach"; and 87.3% of educators selected "Agree" or "Strongly Agree" in response to "I feel knowledgeable about the best strategies to use in job coaching." In terms of comfort integrating strategies into their job coaching roles, 93.1% of educators selected "Agree" or "Strongly Agree" in response to "I feel comfortable integrating specific employment skill strategies in the classroom" and "I feel comfortable integrating specific social-skill training in the classroom."

Perspectives on Student Independence

The majority (92.5%) of educators selected "Agree" or "Strongly Agree" in response to "I think student/employee independence is an important part of job success." When reflecting on the level of independence displayed by their students, 81.5% of educators selected "Agree" or "Strongly Agree" in response to "Most of my students are independent in practicing employment skills"; 77.4% of educators selected "Agree" or "Strongly Agree" in response to "Most of my students are independent in practicing social skills."

Differences in Educator Perspectives

To investigate whether ratings varied by educator role (e.g., special education teacher, paraprofessional, other), years of experience, and gender (e.g., male, female), multiple sets of one-way ANOVAs were used. We chose to look at educator role as a variable because we were interested in learning more about who is serving students with disabilities in job coaching positions. We hypothesized there would be differences in perceptions of training, comfort in integrating employment skills and comfort in integrating social skills based on educator role. We chose to look at years of experience to determine whether the views of job coaching would differ with increased experience. We hypothesized more experienced educators would have different ratings on each item than less experienced educators. The third variable we investigated was gender. We hypothesized there would be differences in mean ratings between males and females. Table 3 displays the one-way ANOVA results presented by survey item.

Survey Item 1

Results indicated that there was no significant difference among educator roles ($F = 2.08$; $p > .05$) in response to Survey Item 1, "I am comfortable being referred to as a job coach." Results indicated, however, there was a statistically significant difference in response to Survey Item 1 based on gender ($F = 2.34$; $p > .05$). The mean response to Survey Item 1 for males was 4.23 (*SD* = .86) whereas the mean response for females was 3.88 (*SD* = 1.02). Results also indicated there was a statistically significant difference in response to Survey Item 1 based on years of experience ($F = 3.23$; $p < .05$). The mean response to Survey Item 1 for educators with 0-5 years of experience was 4.16 (*SD* = .90); the mean response for educators with 6-10 years of experience was 4.2 (*SD* = .84); the mean response for educators with 11-15 years of experience was 4.25 (*SD* = 1.04), and the mean response for educators with 26-30 years of experience was 2.5 (*SD* = 1).

Survey Item 2

Results indicated that there was no significant difference among educator roles ($F = 2.08$; $p > .05$) in response to Survey Item 2, "I have been trained well on how to be a job coach." Results indicated there was, however, a statistically significant difference in response to Survey Item 2 based on gender ($F = 5.24$; $p < .05$). The mean response to Survey Item for males was 4.23 (*SD* = .86) whereas the mean response for females was 3.88 (*SD* = 1.02). Results also indicated there was a statistically significant difference in response to Survey Item 2 based on years of experience ($F = 3.23$; $p < .05$). The mean response to Survey Item 2 for educators with 0-5 years of experience was 4.16 (*SD* = .90); the mean response for educators with 6-10 years of experience was 4.2 (*SD* = .84), and the mean response for educators with 11-15 years of experience was 4.25 (*SD* = 1.04).

Survey Item 3

Results indicated that there was no significant difference among educator roles ($F = .68$; $p > .05$) or gender ($F = 2.19$; $p > .05$) in response to Survey Item 3, "I feel effective in my role as a job coach." Results indicated, however, there was a statistically significant difference in response to Survey Item 3 based on years of experience ($F = 3.02$; $p < .05$). The mean response to Survey Item 3 for educators with 0-5 years of experience was 4.10 (*SD* = .78); the mean response for educators with 6-10 years of experience was 4.38 (*SD* = .69), and the mean response for educators with 11-15 years of experience was 4 (*SD* = 1.41).

Survey Item 4

Results indicated that there was no significant difference among educator roles

Table 3

One-Way ANOVA Results

Survey Item/Variable	SS	*df*	MS	*F*	*p*
I am comfortable being referred to as a job coach.					
Educator Role	5.238	3	1.746	2.08	.105
Between groups	141.964	169	0.84		
Within groups	147.202	172	0.856		
Total					
Gender					
Between groups	4.374	1	4.374	5.24	.023
Within groups	142.828	171	0.835		
Total	147.202	172	0.856		
Years of Experience					
Between groups	17.741	7	2.534	3.23	.003
Within groups	129.461	165	0.785		
Total	147.202	172	0.856		
I have been trained well on how to be a job coach.					
Educator Role					
Between groups	5.238	3	1.746	2.08	.105
Within groups	141.964	169	0.84		
Total	147.202	172	0.856		
Gender					
Between groups	4.374	1	4.374	5.24	.023
Within groups	142.828	171	0.835		
Total	147.202	172	0.856		
Years of Experience					
Between groups	17.741	7	2.534	3.23	.003
Within groups	129.461	165	0.785		
Total	147.202	172	0.856		
I feel effective in my role as a job coach.					
Educator Role					
Between groups	1.429	3	0.476	0.68	.564
Within groups	118.039	169	0.698		
Total	119.468	172	0.695		
Gender					
Between groups	1.512	1	1.512	2.19	.141
Within groups	117.956	171	0.700		
Total	119.468	172	0.695		
Years of Experience					
Between groups	13.566	7	1.938	3.05	.005
Within groups	105.902	165	0.642		
Total	119.468	172	0.695		

Table 3 Continued

Survey Item/Variable	SS	*df*	MS	*F*	*p*
I feel knowledgeable about the best strategies to use in job coaching.					
Educator Role					
Between groups	3.857	3	1.286	1.89	.133
Within groups	114.929	169	0.680		
Total	118.786	172	0.691		
Gender					
Between groups	4.730	1	4.730	7.09	.009
Within groups	114.056	171	0.667		
Total	118.786	172	0.691		
Years of Experience					
Between groups	9.307	7	1.330	2.00	.058
Within groups	109.479	165	0.664		
Total	118.786	172	0.691		
I think student/employee independence is an important part of job success.					
Educator Role					
Between groups	0.386	3	0.129	0.20	.898
Within groups	109.926	169	0.650		
Total	110.312	172	0.641		
Gender					
Between groups	0.102	1	0.102	0.16	.691
Within groups	110.210	171	0.645		
Total	110.312	172	0.641		
Years of Experience					
Between groups	7.211	7	1.030	1.65	.125
Within groups	103.101	165	0.625		
Total	110.312	172	0.641		
I feel comfortable integrating specific employment skill strategies in the classroom.					
Educator Role					
Between groups	0.480	3	0.160	0.33	.802
Within groups	81.382	169	0.482		
Total	81.861	172	0.476		
Gender					
Between groups	2.399	1	2.399	5.16	.024
Within groups	79.462	171	0.465		
Total	81.861	172	0.476		
Years of Experience					
Between groups	3.931	7	0.562	1.19	.312
Within groups	77.930	165	0.472		
Total	81.861	172	0.476		

Table 3 Continued

Survey Item/Variable	SS	*df*	MS	*F*	*p*
Most of my students are independent in practicing employment skills.					
Educator Role					
Between groups	14.951	3	4.984	7.11	.001
Within groups	118.378	169	0.700		
Total	133.329	172	0.775		
Gender					
Between groups	10.041	1	10.041	13.93	.001
Within groups	123.289	171	0.721		
Total	133.329	172	0.775		
Years of Experience					
Between groups	14.624	7	2.089	2.90	.007
Within groups	118.705	165	0.719		
Total	133.329	172	0.775		
I feel comfortable integrating specific social-skill training in the classroom.					
Educator Role					
Between groups	2.397	3	0.799	1.48	.223
Within groups	91.476	169	0.541		
Total	93.873	172	0.546		
Gender					
Between groups	0.642	1	0.642	1.18	.279
Within groups	93.231	171	0.545		
Total	93.873	172	0.546		
Years of Experience					
Between groups	5.961	7	0.852	1.60	.139
Within groups	87.912	165	0.533		
Total	93.873	172	0.546		
Most of my students are independent in practicing social skills.					
Educator Role					
Between groups	10.688	3	3.563	5.01	.002
Within groups	120.260	169	0.712		
Total	130.948	172	0.761		
Gender					
Between groups	2.276	1	2.276	3.02	.084
Within groups	128.672	171	0.752		
Total	130.948	172	0.761		
Years of Experience					
Between groups	12.323	7	1.760	2.45	.021
Within groups	118.625	165	0.719		
Total	130.948	172	0.761		

($F = 1.89$; $p > .05$) or years of experience ($F = 2.00$; $p > .05$) in response to Survey Item 4, "I feel knowledgeable about the best strategies to use in job coaching." Results indicated there was, however, a statistically significant difference in response to Survey Item 4 based on gender ($F = 7.09$; $p < .05$). The mean response to Survey Item 4 for males was 4.26 (*SD* = .78) whereas the mean response for females was 3.90 (*SD* = .89).

Survey Item 5

Results indicated that there was no significant difference among educator roles ($F = 0.20$; $p > .05$), gender ($F = 0.16$; $p > .05$), or years of experience ($F = 1.65$; $p > .05$) in response to Survey Item 5, "I think student/employee independence is an important part of job success."

Survey Item 6

Results indicated that there was no significant difference among educator roles ($F = 0.33$; $p > .05$) or years of experience ($F = 1.19$; $p > .05$) in response to Survey Item 6, "I feel comfortable integrating specific employment skill strategies in the classroom." Results indicated, however, there was a statistically significant difference in response to Survey Item 6 based on gender ($F = 5.16$; $p < .05$). The mean response to Survey Item 7 for males was 4.49 (*SD* = .67) whereas the mean response for females was 4.23 (*SD* = .70).

Survey Item 7

Results indicated there was a statistically significant difference in response to Survey Item 7, "Most of my students are independent in practicing employment skills" based on educator roles ($F = 7.11$; $p < .05$). The mean response to Survey Item 7 for special education teachers was 4 (*SD* = .97); the mean response for paraprofessionals was 4.36 (*SD* = .64); and the mean response for other educators was 3.18 (*SD* = .87). Results indicated there was a statistically significant difference in response to Survey Item 7 based on gender ($F = 13.93$; $p < .05$). The mean response to Survey Item 7 for males was 4.26 (*SD* = .81) whereas the mean response for females was 3.73 (*SD* = .95). Results indicated there was a statistically significant difference in response to Survey Item 7 based on years of experience ($F = 2.89$; $p < .05$). The mean response to Survey Item 7 for educators with 0-5 years of experience was 4.15 (*SD* = .81); the mean response for educators with 6-10 years of experience was 4.11 (*SD* = .91); and the mean response for educators with 11-15 years of experience was 4.38 (*SD* = .74).

Survey Item 8

Results indicated that there was no significant difference among educator roles ($F = 1.48$; $p > .05$), gender ($F = 1.18$; $p > .05$), or years of experience ($F = 1.60$; $p > .05$) in response to Survey Item 8, "I feel comfortable integrating specific social-skill training in the classroom."

Survey Item 9

Results indicated that there was no significant difference among educators based on gender ($F = 3.02$; $p > .05$) in response to Survey Item 9, "Most of my students are independent in practicing social skills." Results indicated there was a statistically significant difference in response to Survey Item 9 based on educator roles ($F = 5.01$; $p < .05$). The mean response to Survey Item 9 for special education teachers was 3.91 (*SD* = .95); the mean response for paraprofessionals was 4.19 (*SD* = .69); and the mean response for other educators was 3.18 (*SD* = .75). Results indicated there was a statistically significant difference in response to Survey Item 9 based on years of experience ($F = 2.45$; $p < .05$). The mean response to Survey

Item 9 for educators with 0-5 years of experience was 3.99 (*SD* = .83); the mean response for educators with 6-10 years of experience was 4.02 (*SD* = .88); and the mean response for educators with 11-15 years of experience was 4.38 (*SD* = .74).

Discussion

Many young adults, including individuals with ID, have goals of obtaining meaningful community-based employment and leading independent lives after completing high school. Secondary transition programs provide opportunities for students with disabilities to receive employment skills instruction both in a variety of settings with direct instruction and support to learn vocational and social skills (Wehman et al., 2021; Wenzel et al., 2022). Job coaches often provide key support for students and have a positive impact on students' independent performance on employment skills as they participate in work-based learning activities (Gilson et al., 2021; Parsons et al., 2001).

We examined the perspectives of 173 educators serving as job coaches for secondary students with disabilities to gain an understanding of how they view their roles and to what extent they feel knowledgeable implementing job coaching strategies to support their students in gaining employment skills. Overall findings from the present study indicate that the majority of educators serving as job coaches (86.7%) perceive their roles as being effective in helping students with disabilities gain employment skills and work-related social skills. These ratings are higher than those reported by educators (*n* = 46) in the in the Job Coaching Academy pilot study after which this survey was modeled. In the pilot study, 57.7% of the treatment group (*n*= 25) and 72.7% of the comparison group (*n* = 21) reported feeling effective in their roles as job coaches (Gilson et al., 2021). Perhaps the educators who had the opportunity to engage in professional development specific to their job coaching duties had an enhanced understanding of the multi-faceted nature of the job coaching role and were more critical of their own effectiveness as job coaches.

Findings from previous studies indicate paraprofessionals serving as job coaches have limited access to training (Breton, 2010; Douglas & Uitto, 2021). The majority of educators in this study (82.6%) indicated they were trained well and prepared for their roles as job coaches regardless of role (i.e., special education teacher, paraprofessional, other). However, differences in ratings related to training were found among educators based on gender and years of experience.

Regardless of role, gender, or years of experience, the majority of educators (92.5%) who participated in this study indicated that student independence is an important part of job success. Although the majority (93.1%) of educators also selected high ratings for the level of comfort in integrating both employment skills strategies and social skills strategies into the classroom, the independence ratings of their students in terms of practicing employment skills (81.5%) and social skills (77.4%) indicate potential for student growth in both areas. In the Job Coaching Academy pilot study, the majority of educators in both the treatment (88.9%) and comparison groups (95.5%) rated student independence as an important part of success (Gilson et al., 2021). Gilson and colleagues (2021) had similar findings with treatment and comparison groups of educators rating independence in practicing employment skills at 14.3% and 9.1% respectively; the ratings by treatment and comparison groups of educators on independence in practicing social skills were 25% and 13.6% respectively. The discrepancy between the educators' comfort with integrating employment and social skills in the classroom and the independent practice of those skills by students indicate a need for the use of evidence-based transition practices.

Limitations and Implications for Future Research

Several limitations should be considered when evaluating the findings of this study. First, since this study focused only on perspectives of job coaches, we did not have the opportunity to formally observe how the job coaches used strategies with students with disabilities in the classroom and work settings. Educator observations have been identified as an important part of improving instruction and outcomes for students with disabilities because they offer the opportunity for an objective view of instructional practices being used along with the chance to provide feedback for how to improve instruction (Johnson et al., 2021; Mason et al., 2021). However, most observation protocols are designed for general education settings where much of the learning is expected to be student-directed and do not meet the unique needs of special education settings where instruction is customized to the needs of individual students (Johnson & Brownell, 2014). Future researchers could incorporate observations of educators serving as job coaches while interacting with students as they practice employment skills in school and/or community settings to explore what coaching strategies educators use to support their students with disabilities to learn employment skills in school-based transition programs.

Second, while the survey results give insight into perspectives of educators serving as job coaches, they did not give participants the opportunity to share in-depth responses describing their experiences. Future researchers may wish to consider utilizing focus groups to collect information from educators in various positions who serve as job coaches. Focus groups are a form of group interview to collect data from multiple participants simultaneously on a specific topic through a structured discussion (Gundomogula, 2020; Kitzinger, 1995). In recent decades the use of focus groups in qualitative research has been on the rise, especially in applied research in education, health, management, and social sciences (Gundomogula, 2020). Focus groups can be an efficient way to collect in-depth perspectives from participants who have knowledge or experience with a topic of interest while encouraging discussion and group interaction (Gundomogula, 2020; Kitzinger, 1995). A moderator or interviewer leads the discussion to elicit responses surrounding a specific topic and facilitate discussion. These discussions are used to gather participants' perspectives and can be useful in exploring why people hold certain views. Future researchers could utilize online platforms (e.g., Skype, Teams, or Zoom) to conduct focus groups including educators from different locations to gather a variety of perspectives.

Third, the participants in this study represent a small sample of educators who chose to opt in through in-person and online recruitment. This may not be a representative sample of educators who serve as job coaches throughout the country or even the state. There were more male than female participants and more special education teachers than paraprofessionals who chose to participate in this study. These demographic differences may have had an impact on educator perspectives. Future researchers may want to do further sampling across school districts of various settings across states.

Fourth, due to a lack of relevant existing tools that could capture our variables of interest, we utilized a novel survey measure that has only one application in prior research. Thus, the measure has limited demonstration of validity and requires more research to determine whether the items accurately convey the intended constructs.

Implications for Practice

The educators participating in this study placed a high value on student/employee independence in the workplace. As teachers, paraprofessionals, and employers plan WBLE for students with disabilities, the goal of increasing student independence should remain at the forefront of all instructional activities. Practitioners implementing transition plans should provide students with direct instruction in employment skills and social skills along with opportunities to practice with fading levels of support. Promoting independence during the transition process during high school will help students prepare for successful post-school employment outcomes. The percentage of ratings in the present study which indicated educators had received the needed training for their roles as job coaches were higher than anticipated based on results of previous studies in this area (Gilson et al., 2017, 2021; Wenzel et al., 2022). Nonetheless, the current study demonstrates that school administrators should continue to incorporate professional development to ensure educators serving in job coaching roles have training in evidence-based practices for increasing employment and social skills for students with disabilities.

Conclusion

Preparing students with disabilities for independence, including successful community-based employment as they transition from high school to adulthood is an essential goal of most secondary educators. Educators must be equipped with strategies to support their students in gaining the necessary employment skills and social skills expected by employers. The goal of this study was to explore the perspectives of educators who serve as job coaches, their experiences with training and implementing coaching strategies designed to increase vocational skills. Our findings indicate educators find student independence in the workplace to be a highly valuable trait along with a need for increased demonstration of independence by their students in both employment skills and social skills.

References

Agran, M., Hughes, C., Thoma, C. A., & Scott, L. A. (2016). Employment social skills: What skills are really valued? *Career Development and Transition for Exceptional Individuals, 39*(2), 111-120. https://doi.org/10.1177/2165143414546741

Blanchett, W. J. (2001). Importance of teacher transition competencies as rated by special educators. *Teacher Education and Special Education, 24*(1), 3–12. https://doi.org/10.1177/088840640102400103

Breton, W. (2010). Special education paraprofessionals: Perceptions of preservice preparation, supervision, and ongoing developmental training. *International Journal of Special Education, 25*(1), 34-45.

Brock, M. E., Cannella-Malone, H. I., Schaefer, J. M., & Page, E. J. (2016). Efficacy of training job coaches to implement evidence-based instructtional strategies. *Journal of Vocational Rehabilitation, 45*(3), 351-364. https://doi.org/10.1177/0888406412474022

Bureau of Labor Statistics (2024). *Persons with a disability: Labor force characteristics – 2023*. U.S. Department of Labor (USDL-24-0349). https://www.bls.gov/news.release/pdf/disabl.pdf

Cannella-Malone, H. I., & Schaefer, J. M. (2017). A review of research on teaching people with significant disabilities vocational skills. *Career Development and Transition for Exceptional Individuals, 40*(2), 67-78. https://doi.org/10.1177/2165143415583498

Carter, E.W., Awsumb, J.M., Schutz, M.A., & McMillan, E.D. (2021). Preparing youth for the world of work: Educator perspectives on pre-employment transition services. *Career Development and Transition for Exceptional Individuals, 44*(3), 161–173. https://doi.org/10.1177/2165143420938663

Douglas, S. N., & Uitto, D. J. (2021). A collaborative approach to paraeducator training. *Beyond Behavior, 30*(1), 4-13. https://doi.org/10.1177/1074295621997177

Gilson, C. B., Carter, E. W., & Biggs, E. E. (2017). Systematic review of instructional methods to teach employment skills to secondary students with intellectual and developmental disabilities. *Research and Practice for Persons with Severe Disabilities, 42*(2), 89–107. https://doi.org/10.1177/1540796917698831

Gilson, C. B., Thompson, C. G., Ingles, K. E., Stein, K. E., Wang, N., & Nygaard, M. A. (2021). The Job Coaching Academy for transition educators: A preliminary evaluation. *Career Development and Transition for Exceptional Individuals, 44*(3), 148-160. https://doi.org/10.1177/2165143420958607

Gundumogula, M. (2020). Importance of focus groups in qualitative research. *International Journal of Humanities and Social Science*, *8*(11), 299-302. https://doi.org//10.24940/theijhss/2020/v8/i11/HS2011-082

Hughes, C., & Carter, E. W. (2012). *The new transition handbook: Strategies high school teachers use that work!* Paul H. Brookes Publishing Co.

Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *BMJ*, *311*(299). https://doi.org/10.1136/bmj.311.7000.299

Kregel, J., Wehman, P., Taylor, J., Avellone, L., Riches, V., Rodrigues, R., & Taylor, D. (2020). *A comprehensive review of evidence-based employment practices for youth and adults with intellectual and other developmental disabilities: Final report.* Rehabilitation Research and Training Center at Virginia Commonwealth University in Richmond, Virginia and Centre for Disability Studies, affiliated with the University of Sydney, Australia. https://engage.dss.gov.au/wp-content/uploads/2022/02/Jobsupport-Evidence-Based-Practices-Review-Final-11.pdf

Johnson, E. S., Reddy, L. A., & Jones, N. D. (2021). Introduction to the special series: Can direct observation systems lead to improvements in teacher practice and student outcomes? *Journal of Learning*

Disabilities, 54(1), 3-5. https://doi.org/10.1177/0022219420944795

Johnson, N. D. & Brownell, M. T. (2014). Examining the use of classroom observations in the evaluation of special education teachers. *Assessment for Effective Intervention, 39*(2), 112-124. https://doi.org/10.1177/1534508413514103

Leedy, P. D., & Ormrod, J. E. (2010). *Practical research: Planning and design*. Pearson.

Mason, R. A., Gunersel, A. B., Irvin, D. W., Wills, H. P., Gregori, E., An, Z. G., & Ingram, P. B., (2021). From the frontlines: Perceptions of paraprofessionals roles and responsibilities. *Teacher Education and Special Education, 44*(2), 97-116. https://doi.org/10.177/0888406419896627

Meltzer, A., Kayess, R., & Bates, S. (2018) Perspectives of people with intellectual disability about open, sheltered and social enterprise employment. *Social Enterprise Journal, 14*(2), 225–244. https://doi.org/10.1108/SEJ-06-2017-0034

Morningstar, M. E., & Benitez, D. T. (2013). Teacher training matters: The results of a multi-state survey of secondary special educators regarding transition from school to adulthood. *Teacher Education and Special Education, 36*(1), 51–64. https://doi.org/10.1177/0888406412474022

Narayan, S., Goreczny, A. J., Haggey, T., & Suess, P. (2023). Supporting employment desires of individuals with intellectual disability: Communication is key. *Inclusion, 11*(4), 258-270. https://doi.org/10.1352/ 2326-6988-11.4.258

Parsons, M. B., Reid, D. H., Green, C. W., & Browning, L. B. (2001). Reducing job coach assistance for supported workers with severe multiple disabilities: An alternative off-site/on-site model. *Research in Developmental Disabilities, 22*(2), 151–164. https://doi.org/10.1016/S0891-4222(01)00064-6

Rooney-Kron, M., & Dymond, S. K. (2021). Teacher perceptions of barriers to providing work-based learning experiences. *Career Development and Transition for Exceptional Individuals, 44*(4), 229-240. https://doi.org/10.1177/2165143420988492

Trainor, A. A., Carter, E. W., Karpur, A., Martin, J. E., Mazzotti, V. L., Morningstar, M. E., Newman, L., & Rojewski, J. W. (2020). A framework for research in transition: Identifying important areas and intersections for future study. *Career Development and Transition for Exceptional Individuals, 43*(1), 5-17. https://doi.org/10.1177/9864551419864551

Wehman, P., Schall, C., Avellone, L., Molinelli Brook, A., Brooke, V., McDonough, J., & Whittenburg, H. (2021). Achieving competitive integrated employment for individuals with intellectual and developmental disabilities. In L. M. Glidden, L. Abbeduto, L. L. McIntyre, & M. J. Tassé (Eds.), *APA handbook of intellectual and developmental disabilities: Clinical and educational implications: Prevention, intervention, and treatment* (pp. 333–355). American Psychological Association. https://doi.org/10.1037/0000195-013

Wenzel, J. D., Fisher, M. H., & Brodhead, M. T. (2022). Preparing job coaches to implement systematic instructional strategies to teach vocational tasks.

Career Development and Transition for Exceptional Individuals, *45*(2), 71-85. https://doi.org/10.1177/21651434211041918

Young, K., & Rooney, D. (2023). Developing soft (employability) skills and work experience opportunities to prepare students with intellectual disability for open employment. *British Journal of Special Education, 50*(4), 427-439. https://doi.org/10.1111/1467-8578.12484

Correspondence concerning this article should be addressed to Heather M. Dulas, University of Houston, Educational Leadership and Policy Studies, 3657 Cullen Blvd., Farish Hall, Suite 112, Houston, TX 77204-5023 E-mail: hdulas@central.uh.edu

How Parents' Expression of Their Meaningful Personal Projects Reflects Their Needs?

Lise Lachance
Université du Québec à Montréal

Suzie McKinnon
CIUSSS Saguenay–Lac-Saint-Jean, CISSS Bas–Saint-Laurent and CISSS Côte-Nord

Louis Cournoyer
Université du Québec à Montréal

Louis Richer
Université du Québec à Chicoutimi

Abstract: Service providers for people with an intellectual disability (ID) recognize the need to support family members and caregivers, but few services directly target their well-being. Therefore, recognizing and supporting parents' needs is critical so they can have equal-life opportunities as others, balancing responsibilities and self-actualization while fostering their child's integration. Studying parents' personal projects reveals what holds significance in their lives and contributes to their well-being. Parents' language and words used to express their projects are indicative of their intentions, confidence, assurance, hope, and commitment. The study examines the way in which parents having a child with an ID express their significant personal projects concerning their different life domains. Recruited in Quebec (Canada), 47 mothers and 33 fathers responded to a semi-structured interview in which they listed their personal projects and selected the five most important for them. Following a qualitative content analysis, the 399 parents' significant personal projects were classified into six categories: 1) hesitant or uncertain, 2) conditional, 3) inoperative intention, 4) self-control intention, 5) operational intention, and 6) continuity. Discussions will focus on tailored support for parents based on project categories, addressing hesitations, overcoming barriers, and maintaining commitment. Support and services should promote the social participation of parents, notably through the realization of their personal projects related to work or leisure.

The family, particularly the parents, plays a leading role in supporting the development and integration of children with an intellectual disability (ID) (Ministère de la Santé et des Services sociaux [MSSS], 2021). Conditions associated with ID increase childcare requirements (Peer & Hillman, 2014; Picard, 2012). It is also typical for parents to encourage their children to participate in activities and to advocate for their rights (Picard et al., 2020).

Service providers for people with an ID recognize their relatives' needs for assistance, as they are key actors in child support (MSSS, 2021). The primary objective of these services is to support parents in their child-rearing responsibilities and enhance their parenting abilities, including providing informational, psychosocial, financial, and legal assistance (MSSS, 2021). The availability of resources remains limited, resulting in lengthy procedures, long waiting lists, a shortage of human resources, etc., and leading parents to complain about difficulty accessing psychological support (Michallet et al., 2020).

Interventions, often in groups, are designed to address parents' psychological adaptation, while reducing stress and depression, by encouraging experience sharing, advice, and networking among families in similar situations (Peer & Hillman, 2014). These services are recognized as essential in helping them cope with their specific challenges, strengthen their resilience, preserve their mental health, and maintain their life and family balance. Therefore, supporting parents and understanding their needs are crucial to ensuring them the same opportunities as other parents, enabling them to fulfill family and social roles, and self-actualize, and maintaining a supportive environment for their child.

The well-being and mental health of individuals are closely linked to intrinsically motivated projects that provide internal rewards (Little, 2020). A key element of human flourishing is pursuing significant personal projects in life (Little & Chambers, 2000; Sirgy, 2021). Projects, encompassing a spectrum from daily activities to life goals, vary in complexity, significance, and engagement, reflecting the diversity of individual ambitions and aspirations (Little & Coulombe, 2015). The engagement in meaningful and manageable projects that generate positive emotions and connect with others contributes to well-being (Little, 2020; Little & Coulombe, 2015).

The personal projects of parents of a child with ID can therefore be closely linked to their well-being, as sources of motivation, balance, fulfillment and emotional support daily. When parents can pursue meaningful personal projects that bring them pleasure, this can contribute to their ability to cope with the challenges associated with raising a child with ID, foster family functioning and adopt a positive perspective on parenthood. Thus, it is important for parents to find a balance between their parental responsibilities and their own needs. As they devote time to their projects, they can replenish and fulfill themselves, increase their self-esteem and feel valued, which can reduce stress and burnout. The support and recognition of their strengths and abilities as parents are key factors in promoting their well-being and assisting them in overcoming obstacles. Recognizing the importance of their personal projects and supporting their ability to pursue them is therefore essential to their well-being.

Consequently, the study of personal projects, which reflect the personality and characteristics of the parents' social environment can provide a deeper understanding of what is important to them and what shapes and gives meaning to their lives. In addition, people's ways of expressing and pursuing their personal projects can provide insight into their search for meaning and coherence, as well as their feelings about their projects and their likelihood of success (Chambers, 2007). By encouraging parents' autonomy and personal development, it is possible to improve their well-being and ability to provide optimum support for their child.

Definition of Personal Projects

There are several terms used to describe the progression or orientation towards ideals, states, or achievements, guided by motivations, values, interests, and priorities as well as individuals' aspirations for their personal and professional development (Cooper & Law, 2018; Helgeson, 2019). Personal projects are distinguished by their concrete nature, their structure around specific objectives, and their role as a bridge between inner desires and external achievements. They refer to intentional actions taken by individuals to create meaning, structure, and relationships in their lives, considering their context (Little, 2000, 2020). These evolve based on experiences, opportunities, and circumstances. They are the product of experiences and the anticipation of future ones (Little & Chambers, 2000) and guide individuals' strategies and resources (Béret, 2002). Motivated by individual aspirations, desires, and needs, they are closely linked to personal identity and values. They reflect a person's short- and long-term goals for flourishing and finding meaning in life. They can be high-level goals (life goals) or concrete actions like a daily to-do list (Little, 2000, 2020). Therefore, they are commonly nested and organized hierarchically based on their abstraction level (Austin & Vancouver, 1996). They can be related to different life domains (e.g., work, family, health) and involve individual or shared activities (Little & Coulombe, 2015). Their pursuit can enhance self-efficacy, happiness, and quality of life, but can lead to stress and difficulties if their achievement is hindered. In sum, personal projects refer to a set of significant, intentional actions undertaken by parents of a child with an ID that reflect their personal characteristics as well as the characteristics of their social environment, including those of the child. From day-to-day activities (e.g., prepare healthy meals) to long-term goals (e.g., development of the child's full potential), they enable to better understand how parents give meaning to their lives, make decisions and act to achieve their goals. They are often linked to their deepest motivations, aspirations, and values, and reveal their concerns in different life domains.

Personal Projects Dimensions

Assessing personal projects across various dimensions can predict outcomes like achievement (Sheldon & Elliot, 1999; Wiese, 2007), well-being (Little, 2020), and life satisfaction (Helgeson, 2019). In a systematic review, Kiendl and Hennecke (2022) identified 1,166 terms reflecting project dimensions. Based on the ranking order, the 20 most frequently evaluated dimensions are importance, progress, commitment, difficulty, self-efficacy, control, stress, intrinsic, outcomes, identified, introjected, efficacy, conflict, effort, likelihood, enjoyment, external, challenge, value, and attainment. They can be grouped in categories: motivation (external, introjected, identified, intrinsic), meaning (importance, commitment, value), manageability (difficulty, challenge, conflict, control, progress, effort, efficacy, self-efficacy, likelihood, outcomes, attainment), social connection, and emotions (enjoyment, stress) (Lachance et al., 2020; Little, 2020).

Meaningful projects can be seen as central as they enhance the sense of life and high engagement in, and the ability to accomplish, such intrinsic projects are positively linked to well-being (Little & Chambers, 2000). Intrinsic projects, aligned with fundamental psychological needs such as competence, autonomy, and relatedness, are recognized as the most effective at enhancing well-being (Ryan et al., 2022) and life satisfaction (Sirgy, 2021), while extrinsic projects, which focus primarily on obtaining external approval and rewards, are linked to lower well-being levels (Ryan et al., 2022).

Research indicates that individual well-being is related to project achievement in various life domains (Sheldon & Elliot, 1999; Wiese, 2007). According to Klug and Maier's (2015) meta-analysis, well-being is more closely correlated with progress than completion. Progress towards a goal is often accompanied by a state of "flow," an emotion that contributes to well-being (Austin & Vancouver, 1996). Locke and Latham (2002) emphasize feedback importance in project accomplishment. Individuals can then adjust their level and direction of effort according to the project requirements. Feedback provides the opportunity to intensify efforts to counter the lack of progress, or conversely, to moderate these efforts and recognize success when objectives are reached (Cooper & Law, 2018). Thus, commitment to a project and efforts to achieve it tends to amplify positive emotions in case of success and negative emotions in case of failure (Sirgy, 2021). However, the difficulty of a project mediates the relationship between progress and well-being, where individuals feel more positive emotions when they make progress towards challenging yet realistic goals (Wiese, 2007). Finally, self-efficacy facilitates the development of effective strategies, perseverance in the face of obstacles, management of negative feedback, and the pursuit of more ambitious goals. Hence, success depends not only on the nature of the challenge itself, but also on how an individual perceives their ability to overcome it (Little & Chambers, 2000).

To summarize, projects and project-related processes have a significant impact on the emotional state of individuals. When they perceive their goals as achievable, feel progress towards them, and ultimately achieve them, they are likely to experience well-being (Cooper & Law, 2018; Little, 2020). By analyzing the projects of the parents of a child with ID, it becomes possible to identify the sources of intrinsic motivation that guide their actions and choices. Studying personal projects helps to understand the cognitive, emotional and behavioral processes involved in planning, implementing and carrying out their projects. It also offers insights into how they manage their projects and overcome the obstacles they encounter or apprehend, as well as the support resources available to them.

Projects' Word Phrasing

The formulation of personal projects reveals valuable information about individuals, including their values, aspirations, interests, motivations, confidence, and psychological well-being (Chambers, 2007). It can also testify to their commitment and organizational skills, as well as project realism, hesitations or conditions linked to their realization, level of confidence in their feasibility, and perceived likelihood of success. The terms used to evoke projects can also distinguish between the desire phase (I want), intentions (I would like, I intend) and actual behavior (I'm doing) (Cooper & Law, 2018).

Project expression or phrasing can also provide insight into how it aligns with an individual's values. As an example, emphasizing notions such as integrity, creativity, altruism, or personal growth may suggest that the project is in harmony with an individual's fundamental values. When individuals describe their projects in a precise, detailed, and coherent manner, it indicates that they have a clear understanding of what is significant to them. Moreover, if individuals' actions and decisions match the principles and beliefs expressed in their projects, they are consistent with their values.

Strong intrinsic motivation is also an indication of a close connection between projects and individuals' values. The clarity, specificity, and commitment expressed in their projects' formulation can attest to individuals' levels of motivation and involvement. Precise and detailed goals generally suggest a strong intention to accomplish something specific (Gollwitzer & Sheeran, 2006). A proactive attitude, commitment, and determination to achieve projects is clearly expressed by action verbs that describe a concrete physical or cognitive action (e.g., "achieve," "accomplish," "attain") or dynamic terms that refer to an ongoing process or action (e.g., "start to," "continue to," or use of verbs in the present progressive form like "I am doing"). In contrast, wording such as "I must," "I need to," or "Avoiding to" reflect feelings of constraint, pressure, or obligation to project completion, indicating extrinsic motivation.

The way a project is structured and articulated can also reveal an individual's ability to plan, anticipate, and manage the steps necessary to complete the project. Projects that are realistically formulated, incorporating an objective assessment of the resources required (time, skills, support, materials, etc.), illustrate an ability to anticipate needs and plan for their achievement. Similarly, a proactive approach to handling the unexpected can be demonstrated by considering potential constraints and obstacles. Project formulation with intermediate stages illustrates the capability to break it down into manageable sub-tasks, facilitating effective progress monitoring and evaluation. Finally, verbs used in the conditional tense suggest actions contingent on certain conditions, or express desires or dreams.

The wording of a project can also provide clues concerning the level of emotional investment made by individuals (e.g., "spend more quality time"). Those evoked with ardor and vivacity (e.g., "dedicate yourself to a meaningful cause," "explore new horizons," "create something original," "inspire others," "mobilize people"), as well as with determination (e.g., "contribute actively," "work hard," "push your limits," "reach a level of expertise") testify to strong commitment. Conversely, disinterested, or disengaged formulations (e.g., "doing a task by obligation," "performing daily routines") may indicate a lack of involvement. These examples illustrate how passion, enthusiasm and determination can be reflected in the formulation of some projects, making them inspiring, motivating and carrying a positive energy towards their realization. The formulation of some projects can also be neutral.

The way in which individuals express their projects can also reflect their self-confidence and their abilities, as well as their likelihood of being carried out. Positive and assertive formulations (e.g., "I'm determined to," "I'm ready to invest in"), characterized by clear, direct, and determined expressions as to the actions to be taken and the objectives to be achieved, can suggest self-confidence and a high level of motivation towards the stated projects. They are often associated with a greater probability of achievement and success. In contrast, hesitant or negative formulations (e.g., "I think I might start," "I'd like to try," "I might consider starting..., but"), characterized by uncertain or ambiguous expressions or with reserves about the actions to be taken or the expected results, can reveal doubts, concerns or obstacles that could hinder the realization of projects due to their perceived complexity (Little, 2020). This type of formulation may attest to a lack of confidence, low motivation, psychological barriers, or external constraints that could impede project progress.

The manner people formulate their projects may be related to their emotional state. For example, individuals who formulate most of their projects as attempts (e.g., "trying to"), avoidance (e.g., “not doing or stopping something”), or action reductions (e.g., “doing less”) may therefore experience lower levels of pleasure, self-efficacy, and well-being (Elliott & Sheldon, 1997). In fact, when an individual "tries to do" something rather than "does it," it may mean that the project will be more challenging to complete and will have a lower probability of success. The individual may also feel less competent or under control and attribute a negative connotation to the context in which the project will be carried out. Similarly, when an individual does something "to avoid another" or wants to reduce its frequency "to do less," the emotions associated with these projects are often more negative (Sirgy, 2021), because the context is likely to be less pleasant and more stressful. A lower level of self-efficacy may also be associated with these projects. In contrast, when an individual wishes to "do more" of something, this may reflect satisfaction or pleasure with the current situation, stronger feelings of competence and control, a less stressful context for achievement, and a higher probability of success. Finally, when individuals mention that they would like to "continue doing" something, the context is generally more pleasant and less stressful, even though this may represent efforts in terms of continuity and the actions may be difficult to maintain. As a result of their higher self-efficacy and the success they have achieved so far, individuals may be more confident in the likelihood that the project will succeed.

By analyzing the terminology parents of a child with an ID use to articulate their projects, researchers and professionals can gain valuable insights into their needs, mindsets, emotional states, and engagement levels. This understanding can help tailor support and interventions to enhance parents' capacity to pursue and achieve meaningful personal projects effectively.

Purpose of the Study and Specific Research Questions

The study aims to highlight the needs of parents having a child with an ID through an analysis of how they express their significant personal projects concerning their different life domains. Indeed, the way they formulate them can lead to a better understanding of their motivations, their degree of confidence in their realization, and their commitment to them. According to the relevant writing, this study also aims to answer the following specific research questions: **Q1**: Considering the meaning behind the words, how can the significant personal projects of parents having a child with an ID be classified? **Q2**: What are the life domains concerned by the different categories of personal projects? **Q3**: Which categories represent the highest priority personal projects? **Q4**: How the project categories characterize themselves in terms of motivation, meaning, manageability, social connection, and emotions?

Method

Procedure

The research was approved by the Ethics Committee of the Centres universitaires intégrés de santé et de services sociaux de la Mauricie-Centre-du-Québec and by the Institutional Committee on Ethics in Research Involving Human Subjects of the Université du Québec à Montréal. This study was conducted in three regions (Saguenay–Lac-Saint-Jean, Bas-Saint-Laurent and Côte-Nord) of Quebec (Canada) among families of a child with an ID aged 6 to 18 receiving services from rehabilitation centers.

A letter was sent by the center's manager informing parents of the ongoing research project and announcing the eventuality that a professional may contact them to provide more details and solicit their participation. During a telephone call, she explained the research objectives, the expectations regarding their participation, and the measures to ensure confidentiality and anonymity of the collected information. In addition, she ensured that the families met the inclusion criteria, namely that they had custody of the child with an ID, that both parents participated in the project in two-parent families, and that the child did not have an autism spectrum disorder. The professional then asked for their consent to forward their contact information to the principal investigator. Afterwards, a research assistant contacted them to schedule a semi-structured interview about their personal projects. Prior to the interview, the parents signed a consent form. For two-parent families, two research assistants conducted interviews simultaneously to avoid parents' consultation.

Study Participants

The sample consists of 47 women and 33 men from 49 families. Almost half of them are traditional or nuclear (50.9%), approximately one fifth (18.4%) are stepfamilies, and nearly a third (30.6%) are single parents. The average conjugal life of parents involved in a couple's relationship is 16.28 years (*SD* = 7.73). The average age of the mothers is 42.93 years old (*SD* = 6.92) while the one of the fathers is 46.81 years old (*SD* = 7.14) ($t(75) = 2.39$, $p < .05$). The parents' educational attainment indicates that 50.6% hold a high school diploma and 49.4% possess a college/university diploma. There is an average of 2.56 children living full-time at home (*SD* = 1.1), but for 16.5% of parents, their only child has an ID. According to the sample, there are 22 girls and 27 boys with an ID, and 55.1% of them are aged 6 to 11, while 44.9% are aged 12 to 18.

Regarding professional lives, most parents (81.0%) are employed, and more than half (55.1%) are part of a dual-income couple. There are 53.3% of single parents active on the labor market. Most respondents (88.9%) hold a regular or permanent job, work outside the home (84.4%) and are working a day schedule (70.3%). Finally, over two thirds (67.9%) report having sufficient resources to meet their family's needs, with 19.2% declaring financial comfort. However, more than a tenth (12.9%) perceive themselves as poor or very poor.

Data Collection

The Personal Project Analysis (PPA; Little, 1983; Little & Chambers, 2000) is a flexible, reliable and valid method for evaluating activities aimed at achieving a personal goal that can be related to a variety of life domains, distinguished by their stage of advancement (in progress, to be completed) and their level of complexity (e.g., take a walk every day, be more patient with children). In some cases, projects require collaboration or involve long-term goals.

As a first step, the parents listed their personal projects. Subsequently, they pinpointed the top five projects and assessed them across 18 dimensions, employing a scale ranging from zero to 10, whose rating label may vary according to dimensions. These attributes aim to define the self-determination associated with each project (Sheldon & Elliot, 1999), the cognitive attitudes towards them, and the emotions they evoke (Little & Coulombe, 2015).

For self-determination, parents were asked to assess each project according to four types of motivation: external regulation (someone or a situation requires it); introjected (ashamed, guilty or anxious feeling if not realized); identified (must be done because it is an important goal); and intrinsic (for the joy and the pleasure that it procures). A relative autonomy index was computed by summing the scores for identified and intrinsic motivations and subtracting the scores for introjected and external regulation motivations (Sheldon et al., 2017). Additionally, three cognitive dimensions were examined: meaning, manageability, and social connection. For meaning, parents provided insights into their engagement with the project (*How engaged are you in this project?*) and its congruency with their values (*To what extent is this project consistent with the values that guide your life?)*. For manageability, they assessed the project's difficulty level (*How difficult do you find it to carry out this project?*), its compatibility with other projects (*What are the consequences of this project on your other ones?*), their feeling of control (*How do you evaluate the control you have in this project?*), their progression level (*How successful have you been in this project so* *far?*), the adequacy of time invested (*How adequate is the amount of time you spend working on this project?*), their feeling of competence (*To what extent do you feel competent to carry out this project?*), and the project's likelihood of success (*How successful do you believe this project will be?*). For social connection, they reported the way others perceive their project (*How important is this project seem to be for people who are close to you?*), the support they receive (*To what extent do you feel this project is supported by people?*), and the compatibility between their projects and those of their loved ones (*What are the repercussions of this project on the ones of people around you?*). Lastly, parents described the positive (pleasure, pride, enthusiasm, hope) and negative (stress, anxiety, sadness, frustration, guilt) emotions experienced while planning or engaging in their projects.

Data Analysis

Analysis was conducted based on the original project formulation from the first stage. Since there were no limitations as to the length of the project formulation, Chambers (2007) suggested that it better reflect the idiosyncratic interpretation of the project. A qualitative content analysis was conducted to examine how parents expressed their five prioritized projects. For one parent, only four projects were evoked. Qualitative content analysis relies on a systematic but flexible approach to exploring the words and expressions used by individuals in interviews (Graneheim & Lundman, 2004), which can provide rich and detailed insights into their thoughts, emotions, needs, and motivations. Furthermore, it is possible to consider the context in which these words or expressions are used for apprehending the underlying meanings and intentions (Elo et al., 2014). Unlike other approaches that rely on predefined codes, qualitative content analysis often allows the induction of codes from the data itself (Hsieh & Shannon, 2005), and may lead to unexpected discoveries. It produces rich and nuanced analyses, essential for understanding participants' complex perspectives (Graneheim & Lundman, 2004).

Parents' prioritized projects were transcribed and imported into separate cells of an Excel spreadsheet for analysis. This software was chosen because of the conciseness of the material to code, the ease of organizing and consulting the information as well as taking notes during analysis, and the possibility to conduct quantitative analyses (Robinson, 2022).

Following repeated reading of the material, the descriptions of the projects evoked by the parents were coded using a mixed categorization process (Schreier, 2012). Some codes were defined *a priori* based on the literature reviewed and the groupings proposed by Chambers (2007), while others emerged from parents’ wording. The first step of coding involved labeling each project description with a code that was close to the original text, paying particular attention to the words and expressions used by the parents. Subsequently, the predefined and emerging codes were compared, refined, and adjusted, then grouped into meaningful categories to interpret the words used in their contexts, as well as the intentions and feelings expressed by the parents. A working definition was developed for each of the categories. Lastly, the entire classification was reviewed to ensure that all project descriptions were consistent with the definition formulated for their respective category. All analysis was carried out jointly by the four researchers. Additionally, the project categories were analyzed using information reported by parents about their priority projects as well as the 18 dimensions of the PPA.

Results

This section defines and describes the project categories identified, and compares them according to motivation, meaning, manageability, social connection, and emotions.

Project Categories, Life Domains Involved, and Priorities

Following a qualitative content analysis, the 399 parents' significant personal projects were classified into six categories: hesitant or uncertain (*n* = 32), conditional (*n* = 30), inoperative intention (*n* = 78), self-control intention (*n* = 8), operational intention (*n* = 112), and continuity (*n* = 139). Continuity projects are most frequently mentioned by parents, followed by operational intention ones. Generally, parents' projects are distributed across categories (see Table 1).

Hesitant or uncertain projects are characterized by the presence of an unclear or uncertain intention that is reflected using terms like "maybe," "try," "at some point" or verbs at the conditional form. This may reflect the absence of a formal project or a lower project priority:

- *Maybe a trip to the U.S. with my best friend at some point.*
- *My goal is to try to get back into shape and start doing other activities again.*
- *At some point, it might be a good idea for us to finish our honeymoon, have the kids babysat and go away for a while, just the two of us, and finish what we'd started.*
- *And at home, we should do renovations, but that's not the priority.*

This project category primarily concerns conjugal life (25.0%) and health (25.0%) and is the most prevalent one for conjugal life (see Table 2). This project category is usually at the fourth or fifth priority rank (see Table 3).

Conditional projects are stated with a precondition for their realization, which leaves room for a certain passivity. This may relate to time (having, finding, taking, allowing to oneself, let ongoing), a lack of resources (e.g., financial), contextual factors (perceived or real) related to the parent's life situation or the action of another person, its conditions or health state:

- *I'd love to go on vacation but for the moment I can't. My wife is ill.*
- *The pleasure of visiting or traveling. For example, I can't take the kid to a museum, because...*
- *Be able to buy my house*
- *It's all about finding moments... I really don't have any of them to actually take care of myself.*

Recreational/leisure activities account for 36.7% of this category, followed by health (23.3%) and living environment (23.3%) (see Table 2). Compared to other categories, this one has the highest proportion of recreational/leisure activities and the lowest proportion of parental projects. Projects in this category are typically ranked in the last two or second place in terms of priority (see Table 3).

Inoperative intention projects report an intention to have or be without mentioning an action. They are frequently expressed through words like "be," "have," or "I would like" and concern mid-to long-term future. They can be a wish, a desire, a wishful

Table 1

Distribution of parents by number of projects per category

Number of projects	Hesitant or uncertain projects (*n* = 32)	Conditional projects (*n* = 30)	Inoperative intention projects (*n* = 78)	Self-control intention projects (*n* = 8)	Operational intention projects (*n* = 112)	Continuity projects (*n* = 139)
1 project	21	20	23	8	29	22
2 projects	4	5	16	0	13	18
3 projects	1	0	2	0	11	17
4 projects	0	0	3	0	6	5
5 projects	0	0	1	0	0	2

Table 2

Distribution of project categories by domains

Domains	Hesitant or uncertain projects (*n* = 32)	Conditional projects (*n* = 30)	Inoperative intention projects (*n* = 78)	Self-control intention projects (*n* = 8)	Operational intention projects (*n* = 112)	Continuity projects (*n* = 139)	Total (*N* = 399)
Work	3 (9.4%)	1 (3.3%)	14 (17.9%)	0 (0.0%)	14 (12.5%)	12 (8.6%)	44 (11.0%)
Schooling	0 (0.0%)	0 (0.0%)	1 (1.3%)	0 (0.0%)	3 (2.7%)	6 (4.3%)	10 (2.5%)
Parenting	2 (6.3%)	1 (3.3%)	15 (19.2%)	0 (0.0%)	12 (10.7%)	19 (13.7%)	49 (12.3%)
Conjugal life	8 (25.0%)	3 (10.0%)	8 (10.3%)	0 (0.0%)	10 (8.9%)	15 (10.8%)	44 (11.0%)
Health	8 (25.0%)	7 (23.3%)	12 (15.4%)	8 (100.0%)	12 (10.7%)	22 (15.8%)	69 (17.3%)
Living environment	5 (15.6%)	7 (23.3%)	11 (14.1%)	0 (0.0%)	30 (26.8%)	12 (8.6%)	65 (16.3%)
Recreational/Leisure	6 (18.8%)	11 (36.7%)	7 (9.0%)	0 (0.0%)	29 (25.9%)	46 (33.1%)	99 (24.8%)
Interpersonal	0 (0.0%)	0 (0.0%)	4 (5.1%)	0 (0.0%)	1 (0.9%)	2 (1.4%)	7 (1.8%)
Intrapersonal	0 (0.0%)	0 (0.0%)	6 (7.7%)	0 (0.0%)	1 (0.9%)	5 (3.6%)	12 (3.0%)

Table 3

Project priority levels by category

Project priority level	Hesitant or uncertain projects (n = 32)	Conditional projects (n = 30)	Inoperative intention projects (n = 78)	Self-control intention projects (n = 8)	Operational intention projects (n = 112)	Continuity projects (n = 139)
1st Priority	5 (15.6%)	4 (13.3%)	19 (24.4%)	4 (50.0%)	24 (21.4%)	24 (17.3%)
2nd Priority	5 (15.6%)	7 (23.3%)	16 (20.5%)	3 (37.5%)	20 (17.9%)	29 (20.9%)
3rd Priority	5 (15.6%)	4 (13.3%)	13 (16.7%)	0 (0.0%)	21 (18.8%)	37 (26.6%)
4th Priority	8 (25.0%)	7 (23.3%)	12 (15.4%)	0 (0.0%)	20 (17.9%)	33 (23.7%)
5th Priority	9 (28.1%)	8 (26.7%)	18 (23.1%)	1 (12.5%)	27 (24.1%)	16 (11.5%)
Mean	3.34	3.27	2.92	1.88	3.05	2.91

thinking concerning intention to be, to have, to obtain, to achieve something to improve one's living conditions or those of one's loved one. It may also reflect the need to recover, therefore, to have or take time for oneself. In the latter case, time represents an intention, unlike conditional projects, where it is a necessary condition for carrying out another project:

- *Be a better parent*
- *In my expectations, I'd like her [my daughter] to be able to relate to people of her own age.*
- *To be in good health, especially for my kids.*
- *I'd like to finalize my things at the cabin. It’s something I've been wanting to do for a long time.*

This project category is mainly related to parenting (19.2%) and work (17.9%) (see Table 2). When the different project categories are taken into account, this is the most prevalent project category for these two domains, as well as for intrapersonal and interpersonal projects. Furthermore, recreational/leisure activities are less represented in this project category than in others. The distribution of this category of project across the priority ranks is fairly even (see Table 3).

Self-control intention projects reflect an intention to regulate or inhibit an action with respect to a behavior deemed harmful to one's physical health. They were frequently expressed with the intention to "avoid," "reduce," or "stop" a behavior and often concerned the consumption of tobacco, alcohol, or some kinds of food:

- *Quit smoking*
- *Lose weight*
- *Drink less soda*

All projects in this category are related to health (see Table 2). It is also the predominant project category for this domain when the different project categories are considered. Generally, this category of project ranks first or second in terms of priority (see Table 3). In fact, these are the projects with the highest priority for the parents who select them.

Operational intention projects are non-initiated, but cognitive or behavioral action intentions are evoked for the purpose of obtaining, being, or doing something. This intention may concern the person directly, or the help, guidance or support offered to a loved one (e.g., children, spouse, friends). It may be about "doing" or "doing more" of something now or in the future. In cases where the intention is to "take time," the parent specifies how the time will be spent:

- *Getting in shape by jogging or running*
- *Fold laundry as I wash it, instead of piling it up.*
- *Playing more video games with the kids, as they ask me all the time.*
- *Take the time to go back to adult school to do my high school in math, physics and history.*

This project category mainly concerns living environment (26.8%) and recreational/leisure activities (25.9%) (see Table 2). When examining the various project categories, this is the predominant one for living environment projects. Moreover, health-related projects are less represented in this category than in the others. According to Table 3, this category of project is fairly evenly distributed across the different priority ranks.

Continuity projects correspond to intentions to continue an action that has already begun. It refers to "continuing to," "being in the process of," "doing more of," or "completing" an ongoing action. It can also be a question of doing something that the parent has already done in reference to habits, routines, or something usual:

- *Continuing yoga*
- *I want to finish my studies to get my degree in special education. I still have 1 ½ year to go.*
- *We're in the process of setting up a country music group.*
- *We're always renovating, and that's a big part of our lives.*
- *I have a project that I pursue every day, and that's to try to make my kids into adults.*
- *Go out more often with my wife.*

According to Table 2, this project category focuses primarily on recreational/leisure activities (33.1%). Further, projects relating to the living environment are less likely to be included in this category than in others. Continuity projects are fairly evenly distributed across the priority ranks (see Table 3).

Comparison of Project Categories According to the Dimensions of the Personal Project Analysis

Means and standard deviations were calculated for the 18 dimensions of the PPA by project categories (see Table 4). Concerning motivations and meaning, self-control intention projects seem to differ from the other categories in several ways. In terms of self-determination, it is the least autonomous. More specifically, parents' motivations for considering such projects are driven by their beliefs that they are important goals (identified motivation) and the requirements of their situation (external regulation). Along with continuity projects, these are the most significant, because they are congruent with parents' values, and they feel more engaged in them. The three project categories with the lowest engagement levels are hesitant or uncertain, conditional, and operational intention projects.

Regarding manageability, continuity projects are distinguished from the other project categories by their lower level of difficulty, as well as perceived higher

Table 4

Means and standard deviations for the 18 dimensions assessed for each category of projects

Dimensions assessed	Hesitant or uncertain projects (*n* = 32)	Conditional projects (*n* = 30)	Inoperative intention projects (*n* = 78)	Self-control intention projects (*n* = 8)	Operational intention projects (*n* = 112)	Continuity projects (*n* = 139)	Total (*N* = 399)
External motivation	4.94 (3.57)	5.23 (4.07)	5.42 (3.74)	7.63 (2.45)	5.48 (3.38)	5.13 (3.74)	5.33 (3.63)
Introjected motivation	3.13 (2.99)	3.32 (3.68)	4.64 (3.50)	4.50 (3.82)	3.22 (3.30)	3.22 (3.53)	3.53 (3.46)
Identified motivation	6.88 (2.51)	7.73 (2.20)	8.12 (1.94)	9.50 (1.07)	6.64 (2.83)	7.47 (2.58)	7.38 (2.55)
Intrinsic motivation	8.09 (1.87)	7.23 (3.19)	7.90 (2.53)	7.25 (2.87)	7.17 (3.07)	7.83 (2.50)	7.62 (2.70)
Relative autonomy index	6.91 (5.65)	6.42 (7.28)	5.95 (6.89)	4.63 (5.37)	5.11 (6.43)	6.95 (6.64)	6.15 (6.59)
Engagement	5.72 (2.77)	5.93 (3.61)	6.87 (2.85)	8.25 (1.91)	5.92 (3.10)	7.99 (2.05)	6.86 (2.87)
Congruency with values	7.53 (2.57)	7.30 (3.05)	7.95 (2.04)	8.63 (2.77)	7.63 (2.25)	8.47 (1.87)	7.97 (2.22)
Difficulty level	4.53 (3.36)	6.90 (3.16)	5.55 (2.94)	7.63 (1.77)	4.68 (3.42)	4.20 (3.09)	4.90 (3.26)
Compatibility with other projects	3.47 (3.23)	5.23 (3.59)	5.77 (3.52)	6.25 (4.33)	3.83 (3.60)	4.38 (3.66)	4.53 (3.66)
Feeling of control	6.63 (2.86)	5.27 (3.26)	5.55 (2.67)	6.88 (2.53)	6.08 (2.96)	6.99 (2.62)	6.29 (2.85)
Progression level	3.81 (2.71)	3.80 (3.27)	4.56 (3.23)	3.63 (2.56)	3.75 (3.01)	6.74 (2.44)	4.96 (3.14)
Adequacy of time invested	4.59 (3.71)	3.97 (3.32)	5.36 (3.49)	2.88 (3.44)	4.81 (3.36)	6.70 (2.67)	5.46 (3.33)
Feeling of competence	7.41 (2.55)	6.37 (3.05)	6.78 (2.91)	6.88 (1.55)	7.06 (2.54)	7.78 (2.07)	7.23 (2.52)
Likelihood of success	7.72 (1.94)	6.72 (3.13)	7.81 (2.16)	7.50 (1.69)	7.78 (2.16)	8.30 (1.81)	7.88 (2.13)
Importance of the project for others	4.39 (3.17)	5.93 (3.54)	6.95 (3.21)	6.50 (4.28)	5.75 (3.44)	6.27 (3.01)	6.09 (3.30)
Social support received	3.56 (3.19)	4.90 (3.77)	6.10 (3.38)	6.50 (3.30)	5.54 (3.49)	6.09 (3.14)	5.65 (3.40)
Compatibility with others' projects	3.71 (3.11)	3.47 (3.65)	4.39 (3.78)	4.13 (4.55)	4.38 (3.65)	4.27 (3.57)	4.22 (3.62)

Positive emotions	7.94 (2.82)	8.53 (1.76)	8.13 (2.35)	8.50 (1.85)	8.19 (2.26)	8.55 (1.84)	8.31 (2.15)
Negative emotions	2.31 (2.32)	3.80 (2.32)	4.44 (3.56)	5.00 (3.12)	3.08 (2.90)	3.14 (3.02)	3.40 (3.14)

likelihood of success, a greater investment of time, a faster pace of progress, and stronger feelings of control and competence. Despite their low level of difficulty, hesitant or uncertain projects, as well as those with operational intentions, are evaluated as less manageable than continuity projects, since parents devote less time to these projects and feel that they progress more slowly. For their part, self-control projects are the most difficult to pursue and are making the least progress. Moreover, they are the projects in which the least time is invested. In spite of this, parents report a strong feeling of control in these projects compared to those in other categories. Furthermore, this category is the most compatible with their other projects. Conditional projects are perceived as among the most difficult to carry out, and correspond to those for which feelings of control and competence are the lowest. Their likelihood of success and time invested are also lower than those of most other project categories. Finally, parents attribute a higher likelihood of success to inoperative intention projects than to many other project categories. It may be due to the amount of time they invest in these projects, the progress they perceive in them, or their compatibility with their other projects. However, the fact remains that these projects are among those with the lowest feeling of control.

Inoperative intention, self-control intention, and continuity projects are those that receive the most support from immediate entourage. This may be due to the importance the people in their lives attach to these three categories, as well as the compatibility between these projects and those of their significant others. Although parents receive less support for their operational intention projects, they are among the most compatible with those of their family members and friends. The conditional projects are the least compatible with those of their surroundings, which may be linked to the parents' lower perception of support. Finally, they report the lowest level of support for hesitant or uncertain projects, which are also perceived as the least important by those around them.

For all project categories, the emotions reported by parents are more positive than negative. More specifically, self-control intention and inoperative intention projects evoke the most negative emotions, while hesitant or uncertain projects elicit the fewest.

Discussion

The aim of the study was to highlight the needs of parents having a child with an ID, by analyzing the way they express their significant personal projects concerning their different life domains. Following a qualitative content analysis, the 399 parents' significant personal projects were classified into six categories: 1) hesitant or uncertain, 2) conditional, 3) inoperative intention, 4) self-control intention, 5) operational intention, and 6) continuity.

In general, parents have projects in more than one category, and the emotions reported about them are predominantly positive. The majority of projects were in continuity or had operational intentions. The results are encouraging, as these projects usually promote individual well-being. Indeed, involvement in meaningful, manageable, and socially connected projects which generate positive rather than negative emotions are related to individual well-being (Little, 2020). Continuity projects provide structure, meaning and stability in an individual's life (Chambers, 2007), while operational intention projects, through their concrete aspects and organization, promote fulfillment and self-efficacy, both of which contribute to personal satisfaction and well-being (Sirgy, 2021).

Parents' prioritization of personal projects reflects their concerns, interests, and life goals, often centered around recreational and leisure activities. It is not surprising that many parents report a significant reduction in free time for personal activity, regardless of whether their child has a disability. Flood et al. (2020) showed that parents felt more comfortable participating in leisure activities with their children rather than by themselves. However, the constant and tailored care required by a child with an intellectual disability (ID) can limit parents' participation in activities they once enjoyed (Picard, 2012). Feelings of guilt and fear of neglecting their child's needs may lead parents to sacrifice their hobbies (Michallet et al., 2020), contributing to social isolation (Al-Krenawi et al., 2011; Emerson & Brigham, 2015). Managing their child's needs can result in stress and exhaustion, diminishing parents' energy and motivation for personal activities (Peer & Hillman, 2014). To facilitate the maintenance or reintroduction of leisure activities, parents require adequate support, including respite services, family support, and community resources (MSSS, 2021).

Nevertheless, the life domains covered by parents' personal projects can vary based on their categories. Firstly, **hesitant or uncertain projects** are primarily related to conjugal life and health, although recreational/leisure activities also occupy significant space. Despite their intrinsic motivation, these projects often occupy lower priority ranks due to hesitations or uncertainties. Consequently, parents may be less engaged with them, prioritizing other more important projects.

The findings are not necessarily surprising, but they can be concerning. Caring for a child with an intellectual disability demands a sustained and continuous commitment (Peer & Hillman, 2014), presenting numerous challenges that may impede parents' prioritization of their conjugal relationship or personal health (Bourke-Taylor et al., 2022). Childcare’s multifaceted responsibilities, including medical appointments and specialized educational interventions, require considerable time and effort, potentially overshadowing other aspects of parents' lives (Michallet et al., 2020). Financial constraints from medical expenses and specialized equipment add stress, compelling parents to increase workloads or seek additional resources (Lachance et al., 2010). Managing family, professional, and personal responsibilities becomes overwhelming, limiting leisure activity participation and affecting conjugal dynamics (Bourke-Taylor et al., 2022). This can lead to communication gaps or emotional distance in relationships (Al-Krenawi et al., 2011). Despite these challenges, many parents find satisfaction in their role, developing skills and coping strategies to manage effectively. Moreover, parents report few negative emotions for this category.

Professionals should focus on understanding hesitations and uncertainties regarding this type of project by adopting active and empathetic listening. In this case, the aim would be to assist parents in clarifying their projects by encouraging them to focus on what is most important to them, while considering the benefits of different projects. By assisting parents in decision-making, professionals can help them weigh the pros and cons, identify their values and life priorities, and consider long-term perspectives. If necessary, they could refer them to additional resources and ensure follow-up.

Regarding **conditional projects**, the content primarily relates to recreational/leisure activities. Many also concern health and living environment. Projects in this category are often low priority and need certain prerequisite conditions to be met for their realization, such as time constraints, the spouse's or child's health condition, a child's capabilities and behavior, financial resources, or flexibility at work. As a result of the difficulty level in completing these projects, parents exhibit lower commitment levels and report diminished feelings of competence and control. These projects are also the least compatible with those of their loved ones, and so they perceive less support from them.

Parents of a child with an ID often encounter obstacles and conditions that impede their personal projects. This project category, characterized by low engagement, time, and effort, as well as slow progression, probably includes many "frozen goals," which are cognitive representations of desired end states that individuals are strongly committed to achieving and are feasible, but are not actively pursued (Davydenko et al., 2019). When projects require resources (time, money, support) not readily available or rely on external factors or others' cooperation, parents may feel limited in controlling their progress. It may be worthwhile for parents who are already struggling to balance multiple responsibilities (Lachance et al., 2010) to carefully consider the prerequisites for a project's realization before assigning it a priority. Similarly, it might be advisable to postpone or reconsider the implementation of frozen projects until the conditions impeding their realization are resolved, particularly if critical prerequisites are not met and other projects or events must be realized before their pursuit. Given the importance of leisure, health, and living-related projects for parental well-being, supporting parents in resolving specific prerequisites is crucial. Finally, it is noteworthy that many recreational/leisure projects also fall under continuity or operational intention categories.

Professionals should work to understand and eradicate the conditions that hinder the implementation of this type of project to empower parents towards action and strengthen their feelings of control and competence. In collaboration with them, they can develop a realistic and achievable action plan to overcome the identified obstacles while keeping track of progress. Additionally, professionals can guide parents towards available support services and act as a source of emotional encouragement by recognizing their struggles, offering problem-solving strategies, stress management techniques, and ways to improve self-confidence.

Inoperative intention projects mainly relate to parenting and work. This category also contains most of the intrapersonal or interpersonal projects. Since these projects are compatible with the other projects of the parents as well as those of their close ones, they invest time in them and receive a lot of support to carry them out. Parents attribute them a high likelihood of success. However, these projects remain among the most negative in terms of emotions and feeling of control.

Many projects in this category are abstract (e.g., being a better parent) (Austin & Vancouver, 1996; Little, 2020) and often reflect life goals or high-level projects that can be implemented by breaking them into smaller and more concrete (or operational) projects (Carver & Scheier, 1982). Projects' achievement brings satisfaction, but the latter is increased when higher-level ones are realized (Little & Coulombe, 2015). High-level projects reveal not only about what individuals are trying to do, but also about what they are trying to be (Austin & Vancouver, 1996). Using verbs such as "be," "have," or "become" to elicit projects, emphasizes a state to achieve or maintain, or a characteristic to develop. This may reflect a broad, long-term goal or an intrapersonal development project. It is important to recognize that the adopted perspective is more distant and may be indicative of a lower sense of control over their achievement. When the parent states a project as "To be in good health, especially for my kids," this reflects a concern more about the outcome than practical measures to achieve it. This can imply passivity, waiting for goals to materialize rather than taking active steps to realize them. Additionally, intrapersonal projects, aimed at self-improvement, can illicit negative emotions and lead to stress, anxiety, uncertainty, or feelings of guilt when failing or experiencing difficulties in progressing (Little & Chambers, 2000). Moreover, when they are unrealistic or focused on too high expectations, these projects can contribute to frustration, dissatisfaction, helplessness, or depression. They may also result in negative emotions when they involve excessive pressure, unfavorable social comparisons, a discrepancy with reality, excessive idealization, or a negative impact on self-esteem.

Professionals should help parents explore motivations, break down high-level projects into smaller ones, and develop an action plan that identifies potential challenges and resources needed. When a project's intention is not well-defined or operationalized, it can lead to ambiguity regarding the necessary actions, targeted objectives, and success indicators. Thus, parents may feel confused or indecisive about steps needed for project completion, which can lead to procrastination, demotivation, or even abandonment. Inoperative intention can hinder monitoring and evaluation of project progress.

Self-control intention projects, for their part, only focus on health and are considered a top priority due to their significance and necessity. They are compatible with the parents' and relatives' values, and parents receive a high level of support for them. Yet, they are seen as the most difficult to pursue and generate the most negative emotions. Despite this, parents report feeling a stronger sense of control over these projects than most other categories and grant them the least amount of time.

Self-control projects, like weight loss, quitting smoking, and changing eating habits, are known as complex and demanding due to conflicts between long-term goals and short-term impulses. Bad habits, providing immediate stress relief, become ingrained despite their harmful long-term effects, and the person's ability to control their behavior is often compromised by social contexts and daily temptations. While the importance of these projects for health is recognized, motivation and willpower may vary, making control a critical factor in breaking bad habits.

To build positive momentum and a stronger sense of control during change, professionals should evaluate motivations, highlight benefits, and set attainable short-term goals for this project category. Acknowledging every minor achievement is key to sustaining motivation and boosting self-efficacy. Additionally, professionals must encourage individuals to view setbacks as learning opportunities rather than failures. Implementing effective self-control (e.g., anticipating risks) and emotional regulation (e.g., meditation) strategies as well as formal or informal support are vital to overcome natural tendencies towards easy options.

On their part, **operational intention projects** focus on the living environment and recreational/leisure activities. Generally, they are perceived as easy and manageable, and among the projects most compatible with those of their loved ones. However, parents' engagement and project progress are often limited by a perceived lack of compatibility with their other ones.

Operational intention projects are characterized by clear and well-defined objectives. This enables individuals to focus on necessary steps and manage resources effectively (Cooper & Law, 2018), reducing stress and anxiety while enhancing the sense of direction and control. Meaningful projects motivate engagement and effort, especially when driven by intrinsic motivation, leading to a greater sense of mastery, accomplishment, and satisfaction.

Professionals should concentrate on validating projects, the steps involved in their implementation, and the means by which they will be completed. In collaboration with parents, they could identify strategies to monitor and optimize progress while directing them to available resources.

Finally, **continuity projects** focus on recreational/leisure activities and are among the most self-determined. Parents find them particularly important since they are aligned with their values. Compared to other categories, they are seen as more manageable because parents feel more control and competence, devote more time to them, and perceive a faster progress rate and a higher success likelihood.

This project category typically brings positive emotions due to its pleasant, less stressful context, offering continuity, emotional stability, and a sense of progress and achievement, thereby fostering self-esteem, self-efficacy, and satisfaction (Chambers, 2007). Long-term personal projects engage individuals meaningfully, allowing them to acquire knowledge and skills and reinforcing their identity (Little, 2020). Such projects meet basic psychological needs and give direction to parents' lives (Ryan et al., 2022). Additionally, continuity projects that include physical activity can directly enhance physical health.

For this project category, professionals can recognize parents' efforts and advancements, discussing challenges and successes to pinpoint effective strategies and areas for improvement. To keep parents engaged, focusing on motivational factors and the benefits of project pursuit is key. Facilitating the exchange of best practices among parents might also be beneficial.

Contributions and Limits

Many studies have examined the experiences of parents having a child with an ID from a negative perspective (e.g., stress, distress). The actual research adopts a more positive approach to the experience of these parents, focusing on their personal projects, a topic seldom addressed in previous studies. Specifically, it explores how these parents articulate their personal projects to better understand their needs, priorities, and aspirations. By documenting their complex realities, this research contributes to raising awareness among researchers and practitioners about their living conditions. It identifies the challenges these parents face in pursuing their projects, suggesting areas where additional interventions and resources could be beneficial. This could influence professional practices, the development of targeted programs, and policy formulation to support and improve the well-being of these parents. By giving them a voice and highlighting their experiences, this research helps to value the expertise and perspectives of parents, who are key players in the life of their child with an ID.

A limitation of this research is its incomplete portrait of the dynamic nature of parents' projects, failing to track how these projects may shift categories over time, especially in the case of conditional projects or "frozen goals." Temporal perspective plays a role in the formulation, pursuit, and realization of personal projects (Austin & Vancouver, 1996). Thus, as changes occur in their lives, parents may modify, adjust, or redefine their projects. Although the realization of a project or progress in it contributes to well-being, it is equally important to be able to disengage from certain projects (Sirgy, 2021). In addition, some parents had difficulty articulating their personal projects and expressing themselves about them. Being asked to respond to questions unfamiliar to them, participants may have felt unexpectedly challenged, which might have limited access to personal projects for analysis. Finally, the results' transferability could be affected, as the study sample already received support from rehabilitation centers, which does not represent the situation of all parents having a child with an ID.

Perspectives for Future Studies

This qualitative research paves the way for correlational studies on the projects of parents having a child with an ID to identify more precisely those most beneficial to their psychological health. Additionally, a mixed method study could investigate parents' word choice to state their projects and establish links with their well-being and quality of life. It could be useful to conduct a longitudinal study to examine the evolution of projects over time as well as the factors facilitating or hindering their implementation. It would also be relevant to analyze personal projects by distinguishing those of mothers and fathers according to some children's characteristics (e.g., age, level of need) to better identify, understand, and target their specific support needs. These research avenues aim to deepen the understanding of the needs, challenges, and aspirations of parents having a child with an ID, as well as to guide the development of more adapted programs and policies to support them.

Conclusion

This article underscores the importance of acknowledging the personal projects of parents having a child with an ID, especially the way they express them. Recognizing these parents' experiences, challenges, and priorities through the analysis of their language offers insights into their mindset, emotions, and commitment levels. Such understanding allows for tailored support and interventions, aiming to empower parents in pursuing and achieving meaningful personal projects. The study suggests various support and services based on project categories, including overcoming hesitations, removing obstacles, operationalizing projects, behavioral changes, project validation, optimizing resources, and maintaining commitment. Support and services should promote the parents' social participation, notably through the realization of their personal projects related to work or leisure. Supporting parents in their personal projects can contribute to improving the family well-being and quality of life.

References

Al-Krenawi, A., Graham, J., & Al Gharaibeh, F. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society*, *26*(2), 139–150. https://doi.org/10.1080/09687599.2011.543861

Austin, J. T., & Vancouver, J. B. (1996). Goal constructs in psychology: Structure, process, and content. *Psychological Bulletin*, *120*(3), 338–375. https://doi.org/10.1037/0033-2909.120.3.338

Béret, P. (2002). Projets professionnels et emplois ultérieurs : Une analyse des mécanismes de l'insertion professionnelle. *L'Orientation Scolaire et Professionnelle*, *31*(2). https://doi.org/10.4000/osp.4776

Bourke-Taylor, H. M., Cotter, C., Joyce, K. S., Reddihough, D. S., & Brown, T. (2022). Fathers of children with a disability: Health, work, and family life issues. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, *44*(16), 4441-4451. https://doi.org/10.1080/09638288. 2021.1910739

Carver, C. S., & Scheier, M. F. (1982). Control theory: A useful conceptual framework for personality-social, clinical, and health psychology. *Psychological Bulletin, 92*(1), 111–135. https://doi.org/10.1037/0033-2909.92.1.111

Chambers, N. C. (2007). Just doing it: Affective implications of project phrasing. In B. R. Little, K. Salmela-Aro, & S. D. Phillips (Eds.), *Personal project pursuit: Goals, action, and human flourishing* (pp. 145–169). Lawrence Erlbaum.

Cooper, M., & Law, D. (2018). *Working with goals in psychotherapy and counselling*. Oxford University Press.

Davydenko, M., Werner, K. M., & Milyavskaya, M. (2019). Frozen goals: Identifying and defining a new type of goal. *Collabra Psychology, 5*(1). https://doi.org/10.1525/collabra.194

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, *4*(1). https://doi.org/10.1177/2158244014522633

Elliot, A. J., & Sheldon, K. M. (1997). Avoidance achievement motivation: A personal goals analysis. *Journal of Personality and Social Psychology, 73*(1), 171–185. https://doi.org/10.1037/0022-3514.73.1.171

Emerson, E., & Brigham, P. (2015). Exposure of children with developmental delay to social determinants of poor health: Cross-sectional case record review study. *Child: Care, Health and Development, 41*(2), 249–257. https://doi.org/10.1111/cch.12144

Flood, S., Meier, A., & Musick, K. (2020). Reassessing parents' leisure quality with direct measures of well-being: Do children detract from parents' down time? *Journal of Marriage and Family, 82*(4), 1326–1339. https://doi.org/10.1111/jomf.12647

Gollwitzer, P. M., & Sheeran, P. (2006). Implementation intentions and goal achievement: A meta-analysis of effects and processes. *Advances in Experimental Social Psychology*, *38*, 69-119. https://doi.org/10.1016/S0065-2601(06)38002-1

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education*

Today, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Helgeson, V. S. (2019). Personal projects and psychological well-being: Emerging adults with and without diabetes. *Journal of Pediatric Psychology*, *44*(2), 176–185. https://doi.org/10.1093/jpepsy/jsy065

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Kiendl, K., & Hennecke, M. (2022). The measurement of goal dimensions: A critical review. *Motivation Science*, *8*(3), 215–229. https://doi.org/10.1037/mot0000268

Klug, H. J. P., & Maier, G. W. (2015). Linking goal progress and subjective well-being: A meta-analysis. *Journal of Happiness Studies*, *16*(1), 37–65. https://doi.org/10.1007/s10902-013-9493-0

Lachance, L., McKinnon, S., Côté, A., Cournoyer, L., Grégoire, S., & Richer, L. (2020). Analysis of personal projects of mothers and fathers having a child with an intellectual disability. *DADD Online Journal*, *7*(1), 79–95. https://exceptionalchildren.org/sites/default/files/2023-04/doj_7_2020.pdf?_gl=1*14d7t23*_ga*MTM5NDk1OTQ3MS4xNzE4OTc0MjQx*_ga_L4ZFTNESGT*MTcxODk3NDI0MS4xLjAuMTcxODk3NDI0MS42MC4wLjA.

Lachance, L., Richer, L., Côté, A., & Tremblay, K. N. (2010). *Étude des facteurs associés à la détresse psychologique des mères et des pères d'un enfant ayant une déficience intellectuelle et de leurs besoins en matière de services selon les caractéristiques de l'enfant*. Université du Québec à Chicoutimi. https://frq.gouv.qc.ca/app/uploads/2021/06/pt_lachancel_annexe-2010_di-detresse-psychologique-parents.pdf

Little, B. R. (1983). Personal projects: A rationale and method for investigation. *Environment and Behavior*, *15*(3), 273–309. https://doi.org/10.1177/0013916583153002

Little, B. R. (2000). Free traits and personal contexts: Expanding a social ecological model of well-being. In W. B. Walsh, K. H. Craik, & R. H. Price (Eds.), *Person environment psychology: New directions and perspectives* (2nd ed., pp. 87–116). Erlbaum.

Little, B. R. (2020). How are you doing, really? Personal project pursuit and human flourishing. *Canadian Psychology*, *61*(2), 140–150. https://doi.org/10.1037/cap0000213

Little, B. H., & Chambers, N. C. (2000). Analyse des projets personnels : Un cadre intégratif pour la psychologie clinique et le counselling. *Revue Québécoise de Psychologie*, *21*(2), 153–190.

Little, B. R., & Coulombe, S. (2015). Personal projects. In J. D. Wright (Ed.), *International encyclopedia of the social & behavioral sciences* (2nd ed., pp. 757–765). https://doi.org/10.1016/b978-0-08-097086-8.26100-x

Locke, E. A., & Latham, G. P. (2002). Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. *American Psychologist*, *57*(9), 705-717. https://doi.org/10.1037/0003-066X.57.9.705

Michallet, B., Julien-Gauthier, F., Marcoux, L., Chesneau, S., & Dumont, C. (2020). Être parent d'un enfant adulte ayant une déficience intellectuelle au Québec : Une étude qualitative exploratoire. *Revue de Psychoéducation*, *49*(2), 259–283. https://doi.org/10.7202/1073996ar

Ministère de la Santé et des Services sociaux [MSSS]. (2021). *Pour une intégration des soins et des services pour les personnes ayant une déficience : Gamme de services pour les personnes ayant une déficience physique, une déficience intellectuelle ou un trouble du spectre de l'autisme*. https://publications.msss.gouv.qc.ca/msss/fichiers/2021/21-824-02W.pdf

Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92–98. https://doi.org/10.1111/jppi.12072

Picard, I. (2012). *Enquête sur les services reçus et les besoins des parents d'une personne présentant une déficience intellectuelle. Création d'un programme de soutien* [Doctoral dissertation, Université du Québec à Montréal]. Archipel. https://archipel.uqam.ca/4640/1/D2300.pdf

Picard, I., Morin, D., & Rutt, K. (2020). Enquête sur les services reçus et les besoins de soutien de parents de personnes présentant une déficience intellectuelle au Québec. *Revue Francophone de la Déficience Intellectuelle*, *30*, 29–44. https://doi.org/10.7202/1075382ar

Robinson, O. C. (2022). Conducting thematic analysis on brief texts: The structured tabular approach. *Qualitative Psychology*, *9*(2), 194–208. https://doi.org/10.1037/qup0000189

Ryan, R. M., Duineveld, J. J., Di Domenico, S. I., Ryan, W. S., Steward, B. A., & Bradshaw, E. L. (2022). We know this much is (meta-analytically) true: A meta-review of meta-analytic findings evaluating self-determination theory. *Psychological Bulletin*, *148*(11-12), 813-842. https://doi.org/10.1037/bul0000385

Schreier, M. (2012). *Qualitative content analysis in practice*. SAGE.

Sheldon, K. M., & Elliot, A. J. (1999). Goal striving, need satisfaction, and longitudinal well-being: The self-concordance model. *Journal of Personality and Social Psychology, 76*(3), 482–497. https://doi.org/10.1037/0022-3514.76.3.482

Sheldon, K. M., Osin, E. N., Gordeeva, T. O., Suchkov, D. D., & Sychev, O. A. (2017). Evaluating the dimensionality of self-determination theory's relative autonomy continuum. *Personality and Social Psychology Bulletin, 43*(9), 1215–1238. https://doi.org/10.1177/0146167217711915

Sirgy, M. J. (2021). *The psychology of quality of life: Wellbeing and positive mental health* (3th ed.). Springer.

https://doi.org/10.1007/978-3-030-71888-6

Wiese, B. S. (2007). Successful pursuit of personal goals and subjective well-being. In B. R. Little, K. Salmela-Aro, & S. D. Philips (Eds.), *Personal project pursuit: Goals, action, and human flourishing.* (pp. 301-328). Lawrence Erlbaum. https://doi.org/10.4324/9781315089928

The research team thanks the managers of the CIUSSS du Saguenay–Lac-Saint-Jean, the CISSS du Bas-Saint-Laurent, and the CISSS de la Côte-Nord for their support, and the professionals at these establishments for help in family recruitment. The research team would also like to acknowledge the invaluable contribution of parents who generously agreed to take part in the research project. This research was supported by a grant from the Fonds de recherche Inclusion sociale (FRIS) and the Office des personnes handicapées du Québec (OPHQ). Correspondence concerning this article should be addressed to Lise Lachance, Département d'éducation et pédagogie, Université du Québec à Montréal, C.P. 8888, Succ. Centre-ville, Montréal (Québec), H3C 3P8, Canada. Email: lachance.lise@uqam.ca

Putting Research into Practice: AAC Strategies for Children with Autism

Rebecca Archer Anwar and Juliet E. Hart Barnett
Arizona State University

Abstract: Language deficits are a common challenge for children with autism spectrum disorder (ASD), with some studies suggesting that 25% to 35% of children with ASD are minimally verbal. One option that may support the communication skills of children with ASD is augmentative and alternative communication (AAC). Though there are legal mandates for AAC use in the public schools, implementation is not an intuitive process, and can be challenging for special education teachers and speech-language pathologists (SLPs). To address this challenge, this review article presents several evidence-based strategies that may be used as a starting point for educators seeking to support children with ASD using AAC systems. Strategies discussed include using multiple AAC modalities in the classroom, aided language modeling, and supportive communication partner behaviors. Each section includes actionable tips that educators may use to assist children with ASD using AAC in the classroom.

Language deficits are a common challenge for children with autism spectrum disorder (ASD) and can be characterized by delays in communication and challenges with social and functional language (Kozlowski et al., 2011; Schaeffer et al., 2023). For some children with ASD, spoken language can be a significant barrier to communication. Though many use spoken language to communicate, some studies suggest that 25% to 35% of children with ASD are minimally verbal (i.e., use fewer than 20 spoken functional words), even after receiving early intervention services (Norrelgen et al., 2015; Rose et al., 2016). These communication difficulties present challenges in educational settings. Children with ASD may require special education services to help them develop and improve functional communication skills, allowing them to access their right to a free and appropriate public education (Individuals with Disabilities Education Act, 2004).

One option that may support the communication skills of children with ASD is augmentative and alternative communication (AAC). AAC refers to a wide range of communication devices, systems, tools, and strategies that support or replace spoken language. AAC falls under the broader umbrella of assistive technology, and is an evidence-based practice, as well as an important component of service delivery for children with autism with communication challenges (Crowe et al., 2022; Ganz et al., 2012). Research has demonstrated AAC has demonstrably helped children with ASD develop spontaneous communication, requesting, receptive vocabulary, and multi-symbol utterances (Alzrayer et al., 2021; Andzik et al., 2021; Brock & Thomas, 2021; Dunn Davison, 2021; Logan et al., 2017). In this paper, we will describe IDEA mandates for AAC use, implementation challenges for teachers and speech-language pathologists (SLPs), and actionable, ready-to-use evidence-based strategies to maximize the benefits of this important technology for children with autism who present significant communication support needs.

Legal Mandates for AAC Use and Implementation Considerations

IDEA (2004) mandates that public schools provide appropriate services and technology to students with disabilities. These services include providing AAC for children with autism based on academic need (IDEA, 2004). This mandate includes providing appropriate training for school teams to ensure that students have the support necessary to develop language and communication skills and engage in academic learning (Johnston et al., 2012). Inadequate training, lack of ongoing support, limited preparation time, unfamiliarity with AAC systems, and challenges identifying effective AAC strategies and resources are common problems reported by special education teachers working with children with autism who use AAC systems (Andzik et al., 2019). These challenges negatively affect educators' ability to provide AAC support within a variety of daily activities (Andzik et al., 2019; Baxter et al., 2012; Da Fonte et al., 2022). As a result, special education teachers estimate that less than 40% of their AAC users are proficient communicators (Andzik et al., 2018).

There are several factors that educators should consider when supporting the communication skills of AAC users with ASD, who represent a wide range of ages, abilities, and communication needs. Effective AAC intervention should address the imbalance between how language is modeled, and how students are expected to communicate expressively, also known as input-output asymmetry (Binger & Light, 2007; O'Neill et al., 2018). Input-output asymmetry refers to when AAC users are given language input auditorily, but then are expected to use AAC systems to communicate expressively. For students to learn to use AAC symbols expressively, educators must ensure that they are modeling use of those symbols in multiple, naturalistic contexts throughout the day using vocabulary and grammatical structures that are functional and relevant to the student (Sennott et al., 2016). Modeling and support should be included throughout a student's typical day within a variety of motivating activities with natural communication partners (Gevarter & Zamora, 2018; Ogletree et al., 2016). Focusing intervention on motivating activities within a student's natural environment can help support some of the challenges unique to students with ASD, such as engagement and generalization (Alzrayer et al., 2021; Gevarter et al., 2021; Griffen et al., 2023).

AAC intervention should also include functional communication training for a variety of purposes. Research and real-world AAC implementation often focuses on helping students with ASD learn to make requests for their needs; however, students also need instruction for other communicative functions using AAC, such as rejecting, commenting, directing, and social language (Light & McNaughton, 2012; Logan et al., 2022; Tager-Flusberg et al., 2005). Classroom implementation with AAC modeling in a variety of contexts should provide ample opportunities to model a variety of communicative functions.

Special education teachers and SLPs have much to consider when supporting AAC use for children with autism in the classroom and may be unsure where to begin when designing classroom supports and activities with AAC users in mind. Furthermore, this process is not intuitive, and educators require adequate training and resources to support AAC users. AAC implementation training is consistent with recommendations from the Office of Educational Technology (OET). In the most recent iteration of the National Educational Technology Plan (NTEP), the OET recommends that school districts foster environments that include technology, such as AAC, by ensuring that educators have access to professional learning supporting digital literacy skills (National Education Technology Plan, 2024). To address this need for high quality professional learning, we review the research literature related to AAC implementation for children with ASD and describe several practical strategies that SLPs and special education teachers may use as a starting point when collaboratively implementing AAC systems in the classroom. Strategies described include using multiple modality options in the classroom, aided language modeling, and communication partner support behaviors (Babb et al., 2019; Binger & Light, 2007; Cardon, 2015; Logan et al., 2022; Ogletree, 2021; O'Neill et al., 2018). Each section includes actionable tips to assist children with autism using AAC in the classroom. Though not an exhaustive review of the literature, the evidence-based strategies presented in this review offer an actionable starting point for SLPs and special education teachers seeking to collaborate to support AAC users with autism, in the context of meaningful classroom activities.

Strategy #1: Ensure Consistent Access to Multiple AAC Modalities

During planning stages, school teams must consider the types of AAC modalities to include in daily classroom routines and activities. AAC can be aided or unaided. Unaided AAC modalities include methods such as gestures and facial expressions and manual signs. Aided modalities require some type of external support, such as a communication board with symbols, computers, handheld mobile devices, or speech generating devices (ASHA, 2024). Furthermore, AAC can be high tech or light tech. High tech options involve using electronic devices such as dedicated speech generating devices, mobile applications for phones or tablets, or computer software programs. Light tech systems include communication books, picture exchange systems, and vocabulary boards. Aided, unaided, high-tech, and light-tech AAC options can be used alone, or in combination, to give a student multiple options to communicate across different contexts (Light & McNaughton, 2012).

Choosing an AAC system for any student is a complex task, requiring school teams to conduct a comprehensive assessment evaluating a student's physical and cognitive needs, personal preferences, and academic strengths and weaknesses (Dietz et al., 2012; Lund et al., 2017; Lynch et al., 2019). Based on these results, teams can determine the type or types of AAC to include in the classroom. There is not necessarily one best AAC system or modality. However, when choosing an AAC system or combination of systems, school teams must consider which AAC modalities will most likely support children with ASD, who have unique challenges encompassing communication and language development, joint attention, visual attention and discrimination, and engagement (Cardon, 2015). The research on AAC modalities indicates that though many children with ASD may use unaided methods with some degree of effectiveness, there is more data suggesting that aided AAC systems lead to better outcomes in vocabulary learning, making requests, and use of spontaneous communication (Curtis, 2012; Ganz, 2015; Gevarter et al., 2013). Manual signs can be a challenge for children with ASD due to deficits in imitation, motor skills, and joint attention, though it is an often-used modality with professionals beginning to implement AAC (Aydin & Diken, 2020; Beukelman & Mirenda, 2013) . Notably, both light-tech systems (such as picture exchange or vocabulary boards) and high-tech systems (such as speech generating devices) aided AAC systems are effective in improving communication outcomes, particularly for making requests (Gevarter & Zamora, 2018; McLay et al., 2015; Morin et al., 2018; Pak et al., 2023). Aided modalities may also enable children to gain targeted skills more quickly (Gevarter et al., 2013; Nam et al., 2018; Nam & Hwang, 2016). Taken together, the evidence suggests that school teams should ensure that both high-tech and light-tech aided AAC options are included along with any unaided options in the classroom to fully support communication and language development. Teams may need to focus on consistently supporting the aided AAC modalities in the classroom, compared to unaided modalities (Gevarter et al., 2013; Nam et al., 2018; Pak et al., 2023).

Finally, selection of AAC modalities to make available in the classroom should consider student preference. AAC modality preferences can vary widely between students and could have an impact on motivation and generalization of communication skills (Bethune & Boyle, 2023). Various studies have shown that children with ASD may prefer high-tech speech-generating devices compared to light-tech picture exchange systems and manual signs (Genç Tosun et al., 2022; McLay et al., 2015; Son et al., 2006; Soto et al., 1993). However, the impact of device preference on communication outcomes for AAC users with ASD is understudied. Bethune and Boyle (2023) examined the acquisition of a functional communication response (e.g., requesting a break) using a picture-based communication system and a speech-generating device, and paired their results with measures of AAC modality preference. They found that the participants learned the functional communication response at relatively equal rates for both the light-tech and high-tech options, suggesting that both modalities were conducive to efficient learning. Importantly, students generalized the learned skills into the classroom setting with their preferred modality. In the case of this study, both participants showed a preference for the SGD modality. This study only assessed two participants, and only targeted requesting as a replacement for disruptive behaviors. However, a meta-analysis from Pak et al. (2023) indicated that young children with autism using high- and low-tech aided AAC had the best results with their preferred modality, regardless of type. More research examining the connection between AAC preference and language outcomes is needed. Current evidence, however, suggests that including a preference assessment to determine a student's preferred AAC modality may improve communication outcomes and foster the AAC user's self-determination (Pak et al., 2023; van der Meer et al., 2011).

Putting Research into Practice: Multiple AAC Modalities

The following specific tips will inform teachers and other educational professionals seeking to implement AAC supports in the classroom:

- **Include multiple AAC modalities in the classroom**. Ensuring that students have multiple options to communicate (also called a "total communication" approach) can help students flexibly choose the AAC modality that fits their needs. Requiring a specific communication modality (e.g., verbal speech or a specific device) can have negative effects on a student's perception of their autonomy and may not adequately support their communication needs (Donaldson et al., 2021).
- **Don't rely on only unaided AAC modalities.** The research evidence suggests that, due to their unique challenges, children with ASD may have difficulty with unaided modalities, such as manual sign (Aydin & Diken, 2020; Beukelman et al., 2012). Access to aided modalities, including light-tech vocabulary boards or speech-generating devices, may be more effective options for many students with ASD (Gevarter et

al., 2013; Nam et al., 2018; Nam & Hwang, 2016).

- **Always keep all AAC options out and available**. Access to AAC facilitates student and staff use of AAC (Donato et al., 2018). AAC access involves having a student's main system available, as well as a plan for backups in place if the main system is unavailable. Strategies that educators may use could include wearing manual boards on lanyards, posting manual boards or AAC symbol icons in multiple locations on the school campus, and/or ensuring that devices are charged and available and accessible every day. School SLPs may have resources available for this purpose (i.e., manual boards, picture supports to put in the classroom, etc.).
-

Strategy #2: Aided Language Modeling

Aided language modeling is a well-established, best-practice strategy to improve language expression and comprehension for children with ASD (Lynch et al., 2018). AAC interventions including aided language modeling are highly effective across various ages, disabilities, and language skills (O'Neill et al., 2018). In aided language modeling, communication partners point to or activate aided AAC symbols while speaking with an AAC user (Binger & Light, 2007; O'Neill et al., 2018). Within an interaction, a communication partner may use the AAC symbols to model their own utterance, or to model language that the AAC user may use to respond to a communicative overture. Depending on the student's needs and language abilities with AAC, the communication partner may model the entire utterance (with grammatical markers), or may only model key words (O'Neill et al., 2018; Sennott et al., 2016). For example, when discussing what the student would like to select for lunch, the teacher might say and model the entire sentence "What do you want for lunch?" using the AAC system; alternatively, he may say the sentence, but only model "what want" on the AAC system. How much is modeled on the AAC system should be tailored to the student's individual communication goals, which can be determined with the collaborative input of the speech-language pathologist (SLP).

Aided language modeling may be used with any AAC system, from core vocabulary boards to speech-generating devices. Unlike a prompt, the child is not expected to immediately imitate modeled AAC symbols to allow the child to observe and map the locations of icons on the system (Biggs et al., 2018). Aided language modeling works well when used in a child's naturalistic environment, making it an ideal strategy for educators to use within the context of curricular activities (Sennott et al., 2016). Indeed, SLPs around the country reported aided language or AAC modeling being a common intervention used within their clinical practice for children with ASD, and often noticed increases in communication using AAC systems (Clarke & Williams, 2020).

One benefit of aided language modeling is that it addresses "input/output asymmetry" (Light & Binger, 1998; Light et al., 1999; O'Neill et al., 2018). Aided language modeling (also called aided language stimulation or AAC modeling in the research literature) addresses this mismatch by ensuring communication partners, such as educators, parents, caregivers, and peers model language using the same visual language system that students are learning to use. If students are expected to learn language, vocabulary, and functional communication skills using AAC, it is essential that classroom activities include frequent modeling of AAC symbols consistent with a student's selected system.

Intentional modeling ensures exposure to the expected language output, increases communication opportunities, and improves communication outcomes (Dada et al., 2022; Dodd & Gorey, 2014).

In a systematic review of empirical studies on aided language modeling interventions, Biggs et al. (2018) found them to be effective in enhancing expressive communication, including improvements in social language, semantics, and grammar. They also found that children using this approach communicated more frequently, employing new vocabulary and more complex grammar structures. Moreover, these positive outcomes were consistent across various communicative functions such as asking questions, making comments, and engaging with peers. Aided language modeling can be implemented by a wide range of communication partners, including teachers, paraprofessionals, and family members (Andzik et al., 2021; Douglas et al., 2022; Kashinath et al., 2021). Supporting these natural communication partners to utilize aided language modeling within the classroom environment has been found to have favorable effects on improving communication outcomes for students with complex communication needs, including those with ASD (Allen et al., 2017; O'Neill et al., 2018).

Logan et al. (2017) conducted a systematic review of interventions with aided AAC to determine the effect of aided AAC intervention on social communication skills specifically for children with ASD. The reviewed studies most frequently targeted making requests, but also included calling attention, acknowledging, and protesting. The results found that aided AAC interventions, including those using aided language modeling, resulted in at least partial improvement over time across the targeted communication functions (Logan et al., 2017). However, reported maintenance and generalization data was mixed, with challenges related to treatment fidelity and validity affecting the confidence the researchers had in the generalizability of the interventions reviewed. Despite these weaknesses, the data suggest that aided AAC interventions, including language modeling, may help support the development of a variety of communication functions, though most studies continue to target requesting (Logan et al., 2017, 2022).

It is crucial that aided language modeling is delivered by a child's natural communication partners within their daily activities, and at a dosage that will make a positive difference for communication development. for children with ASD. Brock and Thomas (2021) examined an aided language modeling intervention with three children with little to no verbal language, one of whom had an autism diagnosis. The children participated in group play-based activities using low-tech communication boards to facilitate communication. Sessions lasted approximately 180 minutes, with approximately 90-120 of those minutes dedicated to the intervention. Aided language modeling was delivered and measured in 15-minute intervals interspersed throughout the session. During these intervals, the clinicians provided at least 30 instances of aided-language modeling and, subsequently, all participants significantly increased their number of one- and two-symbol messages. Alzrayer et al. (2021) found that combining AAC with a natural language paradigm intervention (which involves modeling words or phrases related to a play-based activity) increased use of spontaneous vocalizations and requesting using a speech-generating device by young children with ASD. Though limited in participants, the results of these studies shed light on how aided language modeling embedded within naturalistic activities could have positive effects on communication for children with little verbal language skills, particularly when delivered with a high intensity. Aided language modeling will likely be most effective in increasing the communicative overtures of children with ASD when delivered by educators who model language and communication within the context of natural activities of the school day, as often as possible (Alzrayer et al., 2021; Brock & Thomas, 2021; Logan et al., 2022).

Putting Research into Practice: Aided Language Modeling

The research literature demonstrates that aided language modeling, when used at an appropriate intensity and within naturalistic contexts, can help children with ASD develop functional communication and improve the quantity and quality of their spontaneous language using AAC. To implement this in the classroom, educators may use the following actionable tips:

- **Become familiar with the student's AAC system**. When educators are familiar with a student's AAC system, they are more likely to effectively use the system. As a result, educators will create more opportunities for aided language modeling, which is essential for student learning (Donato et al., 2018). Educators can familiarize themselves with the system by taking time to identify key words they would like to model on the AAC system, pressing buttons to locate needed vocabulary on high-tech systems, and exploring icon locations on light-tech vocabulary boards. Many high-tech speech generating systems also have the capability to look up the icon locations and provide step-by-step instructions for educators to access specific vocabulary words. Educators may consult the speech-generating device's manual to find out how to use the word finding capabilities for different systems.
- **Start by modeling only one or two words per sentence.** Many educators are unfamiliar with their students' AAC systems, and attempting to model full sentences with correct grammatical structures can feel overwhelming. When beginning with aided language modeling, educators may choose to begin with a few high frequency, salient words that can be used across multiple contexts, and are easy to locate to model during a classroom activity. As educators and students increase their familiarity with icon locations, teachers and SLPs can expand their aided language modeling to new vocabulary and grammatical structures.
- **Model in natural contexts across the school day.** Modeling throughout the day requires educators to ensure that AAC systems are always available and ready-to-use. The student's main system should be available, with backups available if the main system is unavailable. Backups could include having manual boards on each students' desk, posing manual boards or AAC icons in multiple locations in the classroom and on campus, or c wearing AAC icons on lanyards. The school SLP may have resources available for this purpose. Consistent access is crucial because it facilitates student and staff use of AAC (Donato, 2018).

Strategy #3: Supportive Communication Partner Behaviors

Natural communication partners, such as teachers, paraprofessionals, and other support staff, have many opportunities to interact with children with ASD. However, working effectively with children with ASD using AAC requires careful planning and support to promote generalization of communication skills to multiple academic contexts (Chung & Stoner, 2016; Stoner et al., 2010). There are several evidence-based supportive behaviors that partners can use to facilitate communication with children with ASD using AAC. The behaviors discussed in this paper include time delay, prompting, and responsivity (Finke et al., 2017; Light & Binger, 1998; Logan et al., 2022; Ogletree, 2021).

Time delay. Time delay occurs when a communication partner provides extended wait time after a conversational turn, allowing AAC users the time and opportunity to process language input, and allow time for a response (Light & Binger, 1998; Logan et al., 2022). Depending on the student's cultural norms, time delay could also be paired with extended eye contact and an expectant facial expression as a cue that the child is expected to respond to the partner's communicative overture. To maintain a "conversational flow" that is typical of spoken language, communication partners often do not provide ample response time for AAC users (Binger et al., 2008). Using time delay is an evidence-based way that communication partners may support AAC users with ASD. In a review of features of AAC intervention strategies, (Logan et al., 2022) found that time delay (either alone or in conjunction with other strategies) is an effective strategy when working with children with ASD. Time delay, when used effectively by communication partners in naturalistic contexts, can help children with ASD increase use of speech-generating devices, make multi-symbol comments, and make requests (Finke et al., 2017; Gevarter et al., 2021; Gevarter & Zamora, 2018; McMillan & Renzaglia, 2014). Educators need to be aware that children with ASD may need more time to process language and respond to communication overtures when using their AAC systems.

Responsivity. Responsivity involves communication partners interpreting the meaning behind the behaviors of AAC users and responding in alignment with that interpreted meaning (Ogletree, 2021; Ogletree & Pierce, 2010). Responsivity involves interpreting early communicative behaviors such as facial expressions, movements, and eye gaze as communicative bids, and modeling language that students may use using AAC. Responsivity is a key component of several interventions targeted to support communication and behavior for children with ASD. For example, in enhanced milieu teaching (EMT), communication partners are trained to respond to a student's behaviors, attribute meaning to them, and model target language to help promote communication and aid in language development (Dunn Davison et al., 2021; Kaiser & Hancock, 2003; Logan et al., 2022). Results from studies using EMT alone or in conjunction with other strategies have shown that it can contribute to positive outcomes in expressive and receptive language, frequency in communication, and making requests in naturally occurring communication situations (Kaiser et al., 1992; Logan et al., 2022). When combined with AAC, naturalistic interventions such as EMT that encourage communication partners to be warmly responsive to children's behaviors in daily interactions can improve requesting objects and action, calling, and commenting for children with ASD (Alzrayer et al., 2021; Brock & Thomas, 2021; Logan et al., 2017). As language develops, partners may also consider expanding the child's messages to model grammatically or semantically complete utterances (Dodd & Gorey, 2014). In this way, AAC users with ASD can develop language through motivating interactions and meaningful activities in the classroom (Alzrayer et al., 2021; Prizant & Wetherby, 1998; Prizant et al., 2000).

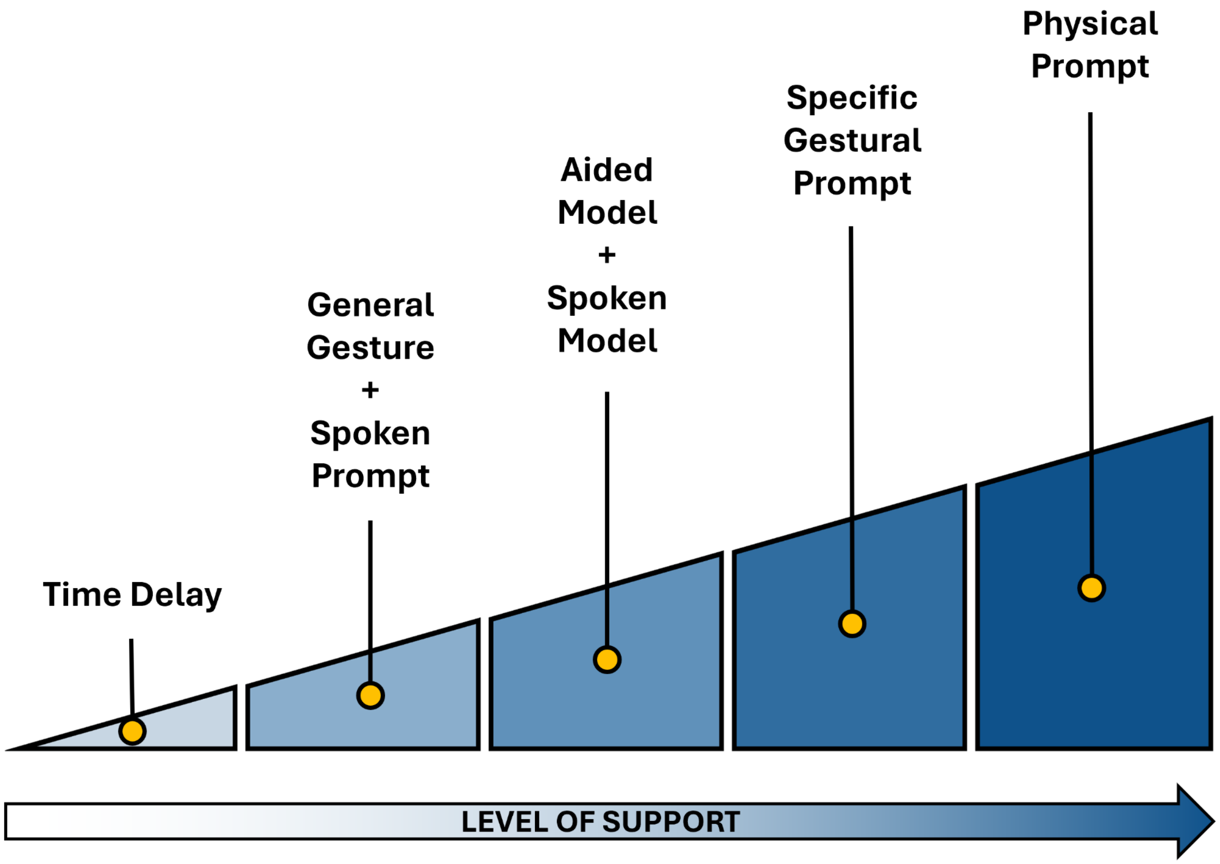
Prompting. Prompting refers to strategies that can be used to scaffold or cue a specific response (Finke et al., 2017; Schreibman et al., 2015). One goal of prompting is to support behaviors that are outside of the child's current skill level. It is beneficial for educators to practice using a least-to-most cueing hierarchy, which involves beginning with the least amount of support, and then systematically adding prompts to attempt to elicit the target skill (Babb et al., 2019). Least-to-most prompting hierarchies often include a variety of prompts, including time delay (described above), gestures, spoken prompts, and modeling of possible responses (Binger et al., 2017; Gevarter et al., 2021; Patterson et al., 2013). An example of what a least-to-most prompting hierarchy may include is presented in Figure 1. Least-to-most prompting hierarchies give students an opportunity to demonstrate targeted skills spontaneously and can improve a variety of skills for children with autism who use AAC, including initiating, phonics skills, increase use of multi symbol messages, name vocabulary from pictures (Ahlgrim-Delzell et al., 2014; Andzik et al., 2021; Finke et al., 2017). Furthermore, using a least-to-most prompting hierarchy can also prevent "prompt dependence", meaning that a student will only use an AAC system to communicate when prompted by a partner (Clark & Green, 2004; Gorgan & Kodak, 2019; Schnell et al., 2020) . By using prompting strategically, educators can help scaffold appropriate supports for children with ASD using AAC systems.

Putting Research into Practice: Supportive Communication Partner Behaviors

To promote the use of communication support partner behaviors, the following tips are recommended:

- **Wait for 8-10 seconds after an utterance before resuming conversation.** After trying to communicate with an AAC user with ASD, wait for 8-10 seconds to allow adequate time for language processing and response formulation. Time delay strategies have been shown in the research literature to be beneficial for children with autism, particularly when learning new AAC icons (Clark & Green, 2004; Logan et al., 2022).
- **Interpret behavior as communication.** What could the student be communicating with their behavior? Model functional language for that need on the student's AAC system. For example, if a student is pushing away a non-preferred item, the teacher could say "It looks like you don't want this" and model "no want" on the AAC system. When teachers interpret behavior as communication, they can show the student language to meet that need using the AAC system (Babb et al., 2019; Paul & Norbury, 2012) .
- **When prompting, start with the least amount of support.** Begin by using a time delay or expectant wait strategy (described above) before adding a gesture, verbal, or visual cue. For example, if a teacher asks the student "What do you want for snack today?", she should first wait 8-10 seconds to see if the student responds in any way. If the student does not respond after the time delay, then she could add a gesture cue (such as gesturing toward picture choices), or a verbal/visual cue (such as "Here are your choices. Can you show me which one you want?").

Figure 1. *Example of a Least-to-Most Prompting Hierarchy*



Collaborative Planning for AAC Users with ASD

To ensure successful implementation, SLPs and special education teachers should collaborate during planning stages and engage in ongoing monitoring throughout implementation (Andzik et al., 2019; Kent-Walsh et al., 2008). This collaboration should focus on identifying appropriate adaptations for activities and the classroom environment using AAC systems to meet the needs of children with ASD. When done effectively, collaboration efforts targeting problem-solving and supporting students across educational contexts can improve student learning, socialization, AAC use across settings, and peer acceptance of AAC (Andzik et al., 2019; Stoner et al., 2010). We have presented several strategies that educators can utilize in the classroom. However, incorporating all these strategies at once may not be feasible, particularly in the learning stages of implementation with team members and students. Therefore, it would be beneficial to begin by planning one or two classroom activities which incorporate these strategies, with the goal of expanding their use to other contexts and eventually using them seamlessly during the school day. For activity ideas or other lesson planning resources, there are several web-based resources that may benefit educators (see Table 1). A planning session between the SLP and special education teacher should include the following discussion topics:

1. **Identify one daily activity to incorporate AAC.** Ideally this activity should occur naturally within the school day and be motivating to the student.
2. **What will the AAC user learn from this activity?** Identify the key concepts and vocabulary or phrases that may be modeled using AAC during the activity. Consider different communication functions that the student with ASD may need to help them in the classroom, including requesting, rejecting, and commenting.
3. **Which AAC strategies would enhance learning?** Ensure that the activity will include structured time for AAC modeling, and explicitly define when this modeling will happen. Identify what level of prompting may be needed and communicate this to staff members. Use visual supports to remind staff members how and when to use the strategies.
4. **Define expectations**. What does success look like for each student? Expectations for success should be individualized to the student's current communication level. For example, one student with ASD may be ready to formulate multi-symbol utterances; another student may be working on interacting with the educator using the AAC system. Each professional working with the student will have specialized knowledge about their needs; therefore, collaboration between team members will allow them to create clear, measurable goals for each student.
5. **Explicitly state the role of communication partners during the activity**. Who will be the student's primary communication partner? What strategies will they use? How will they ensure that they are using the strategies consistently and with fidelity? Collaborating with classroom staff to answer these questions in the planning stages will help ensure that all team members are supporting the students. For example, during a social studies lesson, the teacher's role may be to teach the group lesson and model vocabulary using a word wall with picture supports. The paraprofessional's role, on the other hand, may be to model language directly on a student's AAC system or a vocabulary board attached to the paraprofessional's lanyard.

Conclusion

Children with ASD require specialized support to learn language and communication skills. This support is even more important for children with ASD who need to use AAC systems to help them communicate. Educators, including speech-language pathologists and special education teachers have unique knowledge about the curriculum, student needs, and language development important to effective collaboration when supporting AAC users with ASD. Though not an exhaustive list of all interventions that could benefit this unique group, the AAC strategies presented in this paper represent several evidence-based techniques that may serve as a starting point for educators beginning the collaboration process. Additionally, these strategies are not limited to only certain types of AAC systems or devices; rather, they may be used across any AAC system that students are using in the classroom. Given adequate planning, these immediately actionable techniques may be used across all educational contexts, allowing children with ASD using AAC systems to develop effective communication skills within their natural environment.

Table 1
Web-Based Resources to Support AAC Implementation

Website	Description	Web Address
American Speech-Language-Hearing Association (ASHA) AAC Evidence Map	ASHA presents information from the scientific literature that may be used by SLPs or special educators to inform the decision-making process for AAC users.	https://apps.asha.org/EvidenceMaps/
AAC Language Lab	AAC Language Lab offers education and online resources for AAC, including lesson plans, manual vocabulary boards for various AAC systems, and activity ideas.	https://aaclanguagelab.com
PrAACtical AAC	PrAACtical AAC offers education regarding AAC implementation and strategies for professionals.	https://praacticalaac.org
Talking with Tech	Talking with Tech provides educational podcast episodes about various AAC topics.	https://talkingwithtech.org

References

American Speech-Language-Hearing Association (2024). *Augmentative and Alternative Communication.* https://www.asha.org/public/speech/disorders/aac/

Ahlgrim-Delzell, L., Browder, D., & Wood, L. (2014). Effects of systematic instruction and an augmentative communication device on phonics skills acquisition for students with moderate intellectual disability who are nonverbal. *Education and Training in Autism and Developmental Disabilities*, *49*(4), 517–532. http://www.jstor.org/stable/24582348

Allen, A. A., Schlosser, R. W., Brock, K. L., & Shane, H. C. (2017). The effectiveness of aided augmented input techniques for persons with developmental disabilities: A systematic review. *Augmentative and Alternative Communication* , *33*(3), 149–159. https://doi.org/10.1080/07434618.2017.1338752

Alzrayer, N. M., Aldabas, R., Alhossein, A., & Alharthi, H. (2021). Naturalistic teaching approach to develop spontaneous vocalizations and augmented communication in children with autism spectrum disorder. *Augmentative and Alternative Communication* , *37*(1), 14–24. https://doi.org/10.1080/07434618.2021.1881825

Andzik, N. R., Chung, Y.-C., Doneski-Nicol, J., & Dollarhide, C. T. (2019). AAC services in schools: A special educator's perspective. *International Journal of Developmental Disabilities*, *65*(2), 89–97. https://doi.org/10.1080%2F20473869.2017.1368909

Andzik, N. R., Schaefer, J. M., & Christensen, V. L. (2021). The effects of teacher-delivered behavior skills training on paraeducators' use of a communication intervention for a student with autism who uses AAC. *Augmentative and Alternative Communication* , *37*(1), 1–13. https://doi.org/10.1080/07434618.2021.1881823

Andzik, N. R., Schaefer, J. M., Nichols, R. T., & Chung, Y.-C. (2018). National survey describing and quantifying students with communication needs. *Developmental Neurorehabilitation*, *21*(1), 40–47. https://doi.org/10.1080/17518423.2017.1339133

Aydin, O., & Diken, I. (2020). Studies comparing augmentative and alternative communication systems (AAC) applications for individuals with autism spectrum disorder: A systematic review and meta-analysis. *Education and Training in Autism and Developmental Disabilities*, *55*(2), 119–141.

Babb, S., Gormley, J., McNaughton, D., & Light, J. (2019). Enhancing independent participation within vocational activities for an adolescent with ASD using AAC video visual scene displays. *Journal of Special Education Technology, 34*(2), 120–132. http://dx.doi.org/10.1177/0162643418795842

Baxter, S., Enderby, P., Evans, P., & Judge, S. (2012). Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: A systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders / Royal College of Speech & Language Therapists*, *47*(2), 115–129. https://doi.org/10.1111/j.1460-6984.2011.00090.x

Bethune, K. S., & Boyle, J. (2023). Comparing response modes during functional communication training: Efficacy of acquisition and preference for students with autism. *Focus on Autism and Other Developmental Disabilities*, *38*(2), 101–112. https://doi.org/10.1177/10883576221121276

Beukelman, D. R., & Mirenda, P. (2013). *Augmentative and alternative communication: supporting children and adults with complex communication needs*. Brookes.

Biggs, E. E., Carter, E. W., & Gilson, C. B. (2018). Systematic review of interventions involving aided AAC modeling for children with complex communication needs. *American Journal on Intellectual and Developmental Disabilities, 123*(5), 443–473. https://doi.org/10.1352/1944-7558-123.5.443

Binger, C., Berens, J., Kent-Walsh, J., & Taylor, S. (2008). The effects of aided AAC interventions on AAC use, speech, and symbolic gestures. *Seminars in Speech and Language, 29*(2), 101–111. https://doi.org/10.1055/s-2008-1079124

Binger, C., Kent-Walsh, J., King, M., & Mansfield, L. (2017). Early sentence productions of 3- and 4-year-old children who use augmentative and alternative communication. *Journal of Speech, Language, and Hearing Research*, *60*(7), 1930–1945. https://doi.org/10.1044/2017_JSLHR-L-15-0408

Binger, C., & Light, J. (2007). The effect of aided AAC modeling on the expression of multi-symbol messages by preschoolers who use AAC. *Augmentative and Alternative Communication, 23*(1), 30–43. https://doi.org/10.1080/07434610600807470

Brock, K. L., & Thomas, E. (2021). The effectiveness of aided AAC modeling for Belizean children: A case study. *Perspectives of the ASHA Special Interest Groups, 6*(5), 1182-1197. https://doi.org/10.1044/2021_PERSP-21-00031

Cardon, T. A. (2015). *Technology and the treatment of children with autism spectrum disorder*. Springer International.

Chung, Y.-C., & Stoner, J. B. (2016). A meta-synthesis of team members' voices: What we need and what we do to support students who use AAC. *Augmentative and Alternative Communication*, *32*(3), 175–186. https://doi.org/10.1080/07434618.2016.1213766

Clark, K.M., & Green, G. (2004). Comparison of two procedures for teaching dictated-word/symbol relations to learners with autism. *Journal of Applied Behavioral Analysis, 37*(4), 503-507. https://doi.org/10.1901%2Fjaba.2004.37-503

Clarke, K. A., & Williams, D. L. (2020). Instruction using augmentative and alternative communication supports: Description of current practices by speech-language pathologists who work with children with autism spectrum disorder. *American Journal of Speech-Language Pathology*, *29*(2), 586–596. https://doi.org/10.1044/2019_ajslp-19-00045

Crowe, B., Machalicek, W., Wei, Q., Drew, C., & Ganz, J. (2022). Augmentative and alternative communication for children with intellectual and developmental disability: A mega-review of the literature. *Journal of Developmental and Physical Disabilities, 34*(1), 1–42. https://doi-org /10.1007/s10882-021-09790-0

Curtis, D. B. (2012). *Identifying an optimal and early communication modality for students with autism and intellectual disability* (Publication No. 3510078) [Doctoral dissertation, Lehigh University]. https://www.proquest.com/dissertations-theses/identifying-optimal-early-communication-modality/docview/1022034704/se-2

Dada, S., Tonsing, K., & Goldbart, J. (2022). Friendship experiences of young adults who use augmentative and alternative communication. *International Journal of Disability, Development and Education*, *69*(3), 951–975. https://doi.org/10.1080/1034912X.2020.1746246

Da Fonte, A. M., Boesch, M. C., DeLuca, E. R., Papp, S. K., Mohler, A. E., Holmes, E. E., Clouse, K. A., Young, R. D., & Urbano, R. (2022). Current preparation status in AAC: Perspectives of special education teachers in the United States. *Augmentative and Alternative Communication, 38*(1), 29–40. https://doi.org/10.1080/07434618.2022.2046851

Dietz, A., Quach, W., Lund, S. K., & McKelvey, M. (2012). AAC assessment and clinical-decision making: The impact of experience. *Augmentative and Alternative Communication, 28*(3), 148–159. https://doi.org/10.3109/07434618.2012.704521

Dodd, J. L., & Gorey, M. (2014). AAC intervention as an immersion model. *Communication Disorders Quarterly, 35*(2), 103–107. https://doi.org/10.1177/1525740113504242

Donaldson, A. L., Corbin, E., & McCoy, J. (2021). Everyone deserves AAC: Preliminary study of the experiences of speaking autistic adults who use augmentative and alternative communication. *Perspectives of the ASHA Special Interest Groups, 6*(2), 315-326. https://doi.org/10.1044/2021_PERSP-20-00220

Donato, C., Spencer, E., & Arthur-Kelly, M. (2018). A critical synthesis of barriers and facilitators to the use of AAC by children with autism spectrum disorder and their communication partners. *Augmentative and Alternative Communication, 34*(3). https://doi.org./10.1080/07434618.2018.1493141

Douglas, S. N., Meadan, H., Biggs, E. E., Bagawan, A., Kaori Terol, A. (2022). Building family capacity: Supporting multiple family members to implement aided language modeling. *Journal of Autism and Developmental Disorders, 53*, 2587-2599. https://doi.org/10.1007/s10803-022-05492-4

Dunn Davison, M., Qi, C. H., & Kaiser, A. P. (2021). Enhanced milieu teaching strategies for preschool children with autism spectrum disorder. *Young Exceptional Children*, *24*(4), 191–199. https://doi.org/10.1177/1096250620928335

Finke, E. H., Davis, J. M., Benedict, M., Goga, L., Kelly, J., Palumbo, L., Peart, T., & Waters, S. (2017). Effects of a least-to-most prompting procedure on multisymbol message production in children with autism spectrum disorder who use augmentative and alternative communication. *American Journal of Speech-Language Pathology*, *26*(1), 81–98. https://doi.org/10.1044/2016_ajslp-14-0187

Ganz, J. B. (2015). AAC interventions for individuals with autism spectrum disorders: State of the science and future research directions. *Augmentative and Alternative Communication, 31*(3), 203–214. https://doi.org/10.3109/07434618.2015.1047532

Ganz, J. B., Earles-Vollrath, T. L., Heath, A. K., Parker, R. I., Rispoli, M. J., & Duran, J. B. (2012). A meta-analysis of single case research studies on aided augmentative and alternative communication systems with individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *42*(1), 60–74. https://doi.org/10.1007/s10803-011-1212-2

Genç Tosun, D., Köse, H., Okatan, I. (2022). Examining the augmentative and alternative communication systems preferences of individuals with autism spectrum disorder. *HAYEF Journal of Education*, *19*(2), 146–154. https://hayefjournal.org/en/examining-the-augmentative-and-alternative-communication-systems-preferences-of-individuals-with-autism-spectrum-disorder-13747

Gevarter, C., Groll, M., Stone, E., & Medina Najar, A. (2021). A parent-implemented embedded AAC intervention for teaching navigational requests and other communicative functions to children with autism spectrum disorder.

Augmentative and Alternative Communication, *37*(3), 180–193. https://doi.org/10.1080/07434618.2021.1946846

Gevarter, C., O'Reilly, M. F., Rojeski, L., Sammarco, N., Lang, R., Lancioni, G. E., & Sigafoos, J. (2013). Comparing communication systems for individuals with developmental disabilities: A review of single-case research studies. *Research in Developmental Disabilities*, *34*(12), 4415–4432. https://doi.org/10.1016/j.ridd.2013.09.017

Gevarter, C., & Zamora, C. (2018). Naturalistic speech-generating device interventions for children with complex communication needs: A systematic review of single-subject studies. *American Journal of Speech-Language Pathology, 27*(3), 1073–1090. https://doi.org/10.1044/2018_ajslp-17-0128

Gorgan, E. M., & Kodak, T. (2019). Comparison of interventions to treat prompt dependence for children with developmental disabilities. *Journal of Applied Behavior Analysis*, *52*(4), 1049–1063. https://doi.org/10.1002/jaba.638

Griffen, B., Holyfield, C., Lorah, E. R., & Caldwell, N. (2023). Increasing linguistic and prelinguistic communication for social closeness during naturalistic AAC instruction with young children on the autism spectrum. *Augmentative and Alternative Communication*, 1–14. https://doi.org/10.1080/07434618.2023.2283846

Individuals with Disabilities Education Act (2004). Public Law No. 108-446, 118 Stat 2674. https://sites.ed.gov/idea/regs/b/b/300.105

Johnston, S. S., Reichle, J., Feeley, K. M., & Jones, E. A. (2012). *AAC strategies for individuals with moderate to severe disabilities.* Brookes Publishing Company.

Kaiser, A. P., & Hancock, T. B. (2003). Teaching parents new skills to support their young children's development. *Infants and Young Children*, *16*(1), 9. http://dx.doi.org/10.1097/00001163-200301000-00003

Kaiser, A. P., Yoder, P. J., & Keetz, A. (1992). Evaluating milieu teaching. In S.F. Warren and J. E. Richle (Eds.), *Causes and Effects in Communication and Language Intervention* (pp. 9–47). Brookes.

Kashinath, S., Dukhovny, E., & Polit, P. (2021). Effects of a coaching intervention on paraeducator use of aided language modeling in classroom settings: A pilot investigation. *Communicate Disorders Quarterly, 44*(1), 33-44. https://doi.org/10.1177/15257401211046871

Kent-Walsh, J., Stark, C., & Binger, C. (2008). Tales from school trenches: AAC service-delivery and professional expertise. *Seminars in Speech and Language*, *29*(2), 146–154. https://doi.org/10.1055/s-2008-1079128

Kozlowski, A. M., Matson, J. L., Horovitz, M., Worley, J. A., Neal, D. (2011). Parents' first concerns of their child's development in toddlers with autism spectrum disorders. *Developmental Neurorehabilitation, 14*(2), 72-78. https://doi.org/10.3109/17518423.2010.539193

Light, J., & Binger, C. (1998). *Building communicative competence with individuals who use augmentative and alternative communication*. Brookes.

Light, J. C., Binger, C., Agate, T. L., & Ramsay, K. N. (1999). Teaching partner-focused questions to individuals who use augmentative and alternative communication to enhance their communicative competence. *Journal of*

Speech, Language, and Hearing Research, 42(1), 241–255. https://doi.org/10.1044/jslhr.4201.241

Light, J., & McNaughton, D. (2012). The changing face of augmentative and alternative communication: past, present, and future challenges. *Augmentative and Alternative Communication, 28*(4), 197–204. https://doi.org/10.3109/07434618.2012.7370

Logan, K., Iacono, T., & Trembath, D. (2017). A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. *Augmentative and Alternative Communication, 33*(1), 51–64. https://doi.org/10.1080/07434618.2016.1267795

Logan, K., Iacono, T., & Trembath, D. (2022). A systematic search and appraisal of intervention characteristics used to develop varied communication functions in children with autism who use aided AAC. *Research in Autism Spectrum Disorders, 90,* 101896. https://doi.org/10.1016/j.rasd.2021.101896

Lund, S. K., Quach, W., Weissling, K., McKelvey, M., & Dietz, A. (2017). Assessment with children who need augmentative and alternative communication (AAC): Clinical decisions of AAC specialists. *Language, Speech, and Hearing Services in Schools, 48*(1), 56-68. https://doi.org/10.1044/2016_lshss-15-0086

Lynch, Y., Murray, J., Moulam, L., Meredith, S., Goldbart, J., Smith, M., Batorowicz, B., Randall, N., & Judge, S. (2019). Decision-making in communication aid recommendations in the UK: Cultural and contextual influencers. *Augmentative and Alternative Communication*, *35*(3), 180–192. https://doi.org/10.1080/07434618.2019.1599066

McLay, L., van der Meer, L., Schäfer, M. C. M., Couper, L., McKenzie, E., O'Reilly, M. F., Lancioni, G. E., Marschik, P. B., Green, V. A., Sigafoos, J., & Sutherland, D. (2015). Comparing acquisition, generalization, maintenance, and preference across three AAC options in four children with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *27*(3), 323–339. https://doi.org/10.1007/s10882-014-9417-x

McMillan, J. M., & Renzaglia, A. (2014). Supporting speech generating device use in the classroom part two: Student communication outcomes. *Journal of Special Education Technology*, *29*(3), 49–61. http://dx.doi.org/10.1177/016264341402900304

Morin, K. L., Ganz, J. B., Gregori, E. V., Foster, M. J., Gerow, S. L., Genç-Tosun, D., & Hong, E. R. (2018). A systematic quality review of high-tech AAC interventions as an evidence-based practice. *Augmentative and Alternative Communication*, *34*(2), 104–117. https://doi.org/10.1080/07434618.2018.1458900

Nam, S., Kim, J., & Sparks, S. (2018). An overview of review studies on effectiveness of major AAC systems for individuals with developmental disabilities including autism. *Journal of Special Education Apprenticeship*, *7*(2), 6. https://doi.org/10.58729/2167-3454.1071

Nam, S. S., & Hwang, Y. S. (2016). Acquisition of picture exchange-based vs. signed mands and implications to teach functional communication skills to children with autism. *The Journal of Special Education Apprenticeship*, *5*(2),

1. https://doi.org/10.58729/2167-3454.1052

Norrelgen, F., Fernell, E., Eriksson, M., Hedvall, Å., Persson, C., Sjölin, M., Gillberg, C., & Kjellmer, L. (2015). Children with autism spectrum disorders who do not develop phrase speech in the preschool years. *Autism: The International Journal of Research and Practice*, *19*(8), 934–943. https://doi.org/10.1177/1362361314556782

Ogletree, B. T. (2021). *Augmentative and alternative communication: Challenges and solutions*. Plural Publishing.

Ogletree, B. T., Bartholomew, P., Kirksey, M. L., Guenigsman, A., Hambrecht, G., Price, J., & Wofford, M. C. (2016). Communication training supporting an AAC user with severe intellectual disability: Application of the communication partner instruction model. *Journal of Developmental and Physical Disabilities*, *28*(1), 135–152. http://dx.doi.org/10.1007/s10882-015-9444-2

Ogletree, B. T., & Pierce, H. K. (2010). AAC for individuals with severe intellectual disabilities: Ideas for nonsymbolic communicators. *Journal of Developmental and Physical Disabilities*, *22*(3), 273–287. http://dx.doi.org/10.1007/s10882-009-9177-1

O'Neill, T., Light, J., & Pope, L. (2018). Effects of interventions that include aided augmentative and alternative communication input on the communication of individuals with complex communication needs: A meta-analysis. *Journal of Speech, Language, and Hearing Research, 61*(7), 1743-1765. https://doi.org/10.1044/2018_jslhr-l-17-0132

Pak, N. S., Bailey, K. M., Ledford, J. R., & Kaiser, A. P. (2023). Comparing interventions with speech-generating devices and other augmentative and alternative communication modes: A meta-analysis. *American Journal of Speech-Language Pathology*, *32*(2), 786–802. https://doi.org/10.1044/2022_ajslp-22-00220

Patterson, J. L., Rodríguez, B. L., & Dale, P. S. (2013). Response to dynamic language tasks among typically developing Latino preschool children with bilingual experience. *American Journal of Speech-Language Pathology*, *22*(1), 103–112. https://doi.org/10.1044/1058-0360(2012/11-0129)

Paul, R., & Norbury, C. (2012). *Language disorders from infancy through adolescence.* Elsevier Health Sciences (E-Book).

Prizant, B. M., & Wetherby, A. M. (1998). Understanding the continuum of discrete-trial traditional behavioral to social-pragmatic developmental approaches in communication enhancement for young children with autism/PDD. *Seminars in Speech and Language, 19*(4), 329–352. https://doi.org/10.1055/s-2008-1064053

Prizant, B. M., Wetherby, A. M., & Rydell, P. J. (2000). Communication intervention issues for children with autism spectrum disorders. *Autism Spectrum Disorders: A Transactional Developmental Perspective.* Paul H. Brooks Publishing. https://doi.org/u/10.1002/14651858.cd012324.pub2

Rose, V., Trembath, D., Keen, D., & Paynter, J. (2016). The proportion of minimally verbal children with autism spectrum disorder in a community-based early intervention programme. *Journal of Intellectual Disability Research*, *60*(5), 464–477. https://doi.org/10.1111/jir.12284

Schaeffer, J., Abd El-Raziq, M., Castroviejo, E., Durrleman, S., Ferré, S., Grama, I., Hendriks, P., Kissin, M., Manenti, M., Marinis, T., Meir, N., Novogrodsky, R., Perovic, A., Panzeri, F., Silleresi, S., Sukenik, S., Vicente, A., Zebib, R., Prévost, P., & Tuller, L. (2023). Language in autism: Domains, profiles, and co-occurring conditions. *Journal of Neural Transmission, 130*, 433-457. https://doi.org/10.1007/s00702-023-02592-y

Schnell, L. K., Vladescu, J. C., Kisamore, A. N., DeBar, R. M., Kahng, S., & Marano, K. (2020). Assessment to identify learner-specific prompt and prompt-fading procedures for children with autism spectrum disorder. *Journal of Applied Behavior Analysis*, *53*(2), 1111–1129. https://doi.org/10.1002/jaba.623

Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., Kasari, C., Ingersoll, B., Kaiser, A. P., Bruinsma, Y., McNerney, E., Wetherby, A., & Halladay, A. (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(8), 2411–2428. https://doi.org/10.1007%2Fs10803-015-2407-8

Sennott, S. C., Light, J. C., & McNaughton, D. (2016). AAC modeling intervention research review. *Research and Practice for Persons with Severe Disabilities, 41*(2), 101–115. https://doi.org/10.1177/1540796916638822

Son, S. H., Sigafoos, J., O'Reilly, M., & Lancioni, G. E. (2006). Comparing two types of augmentative and alternative communication systems for children with autism. *Pediatric Rehabilitation*, *9*(4), 389–395. https://doi.org/10.1080/13638490500519984

Soto, G., Belfiore, P. J., Schlosser, R. W., & Haynes, C. (1993). Teaching specific requests: A comparative analysis on skill acquisition and preference using two augmentative and alternative communication aids. *Education and Training in Mental Retardation*, *28*(2), 169–178. https://www.jstor.org/stable/23878852

Stoner, J. B., Angell, M. E., & Bailey, R. L. (2010). Implementing augmentative and alternative communication in inclusive educational settings: A case study. *Augmentative and Alternative Communication, 26*(2), 122-135. https://doi-org/10.3109/07434618.2010.481092

Tager-Flusberg, H., Paul, R., & Lord, C. (2005). *Language and communication in autism. Handbook of autism and pervasive developmental disorders: Diagnosis, development, neurobiology, and behavior.* John Wiley & Sons.

United States Office of Educational Technology (2024). *A call to action for closing the digital access, design, and use divides: 2024 National Education Technology Plan.* U.S. Department of Education. https://tech.ed.gov/netp/

van der Meer, L., Sigafoos, J., O'Reilly, M. F., & Lancioni, G. E. (2011). Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: A review of the literature. *Research in Developmental Disabilities*, *32*(5), 1422–1431. https://doi.org/10.1016/j.ridd.2011.02.003

Correspondence concerning this article should be addressed to Rebecca Archer Anwar, Mary Lou Fulton Teacher's College, Arizona State University, 1050 S Forest Mall, Tempe, AZ 85281. E-mail: rarcher1@asu.edu

Feasibility of Interprofessional Education around Autism Spectrum Disorders

Erin Rotheram-Fuller, Kassandra Spurlock, Maria Dixon and Nancy Scherer
Arizona State University

Abstract: Students with autism spectrum disorders (ASD) and other complex disabilities often require multiple professionals to support their needs, but therapies and support are still often delivered by professionals in isolation. To address this need for collaboration, an interprofessional education (IPE) program was developed between special education and speech and hearing sciences students at the master's level. The program uses collaborative curriculum content, assignments, and applied experiences to increase understanding of multiple related professions and practice in collaboration skills. Three scholar cohorts (n=16) have participated in the program. Two cohorts (n=10) having completed all activities and graduated (n=1 left the program before initiating activities), and the third cohort (n=5) is halfway through. Feasibility of the program was evaluated using: recruitment and retention, fidelity, acceptability, and engagement examined through admissions and retention data and scholar performance and feedback in program activities. Scholars were from diverse backgrounds, with a primary desire to study ASD based on personal family or prior work experience. The program was found to be feasible, as 1) a diverse group of scholars were recruited with 94% retention in the program so far; 2) all scholars have been able to participate in the program on top of their original degree program requirements; 3) program activities have been rated highly by the scholars; and 4) scholars performed well in collaborative coursework and assignments and feel prepared to engage in collaborative professional activities around ASD upon graduation. Specific barriers and recommendations in the program development process are highlighted.

Over the past decade, there has been a significant rise in the diagnosis of developmental disabilities among children in the United States. According to Zablotsky and colleagues (2019), autism spectrum disorders (ASD) has been identified as the fastest-growing developmental condition in the nation between 2009-2017. In 2020, the Centers for Disease Control (2023) found that one in 36 children in the United States were diagnosed with ASD, which represents an 18% increase since the previous report two years prior. With this increasing prevalence, there is a growing need for all professionals to have a better understanding of the unique needs around ASD, and how to coordinate care with other professionals.

Students with ASD and other complex disabilities often require support from multiple professionals to support their needs. A child may require the support of multiple teachers, including both special and general educators, as well as paraprofessionals, therapists, community services providers, case managers, behavior analysts, and more. The Council for Exceptional Children (CEC) has identified collaboration between these teams of professionals as a high-leverage practice associated with professional satisfaction and positive student outcomes (McLesky et al., 2017). Collaboration has demonstrated a strong impact (effect size = 0.93) on student achievement (DuFour, 2007; Hattie, 2008; McLesky et al., 2017), and is associated with better attitudes toward school and lower rates of problem behaviors for students (Griffiths et al., 2021). While the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA, 2006) requires that the individualized education program (IEP) team work collaboratively to ensure all the needs of the child are addressed, once goals are set, many professionals continue to operate in isolation (Pfeiffer et al., 2019). The integration of services, communication, evaluation, and training among professionals is crucial, especially for students with complex needs, to ensure the fulfillment of state educational standards and overall success (Nunez, 2015). The first step in ensuring collaborative practice is to train professionals in these practices as they are learning about the field.

Interprofessional Education (IPE)

Interprofessional education (IPE; Barr et al., 2005) focuses on training professionals in collaborative activities *before* they enter practice, thereby fostering their collaborative skills and promoting a culture of teamwork. To best ensure early career practitioners enter the field prepared to engage in meaningful collaboration, pre-service preparation programs are encouraged to provide interdisciplinary instruction and practice opportunities in the implementation of collaborative structures. However, most current professional training programs specialize in only one area of focus (Shoffner & Wachter Morris, 2010), and each program has a high number of competencies to master within their own discipline.

The demand for special education teachers (SETs) and related service providers in the United States is growing (U.S. Department of Education, 2022), but there's a shortage of high-quality training programs to meet this demand, especially for children with ASD who are culturally and linguistically diverse and have high-intensity needs (Hsiao & Sorenson Peterson, 2019). Since communication is a core diagnostic symptom of ASD (American Psychiatric Association [APA], 2013), they are often referred to speech language pathologists (SLPs) within school and clinical settings to increase language production and improve functional and social-pragmatic language. SETs have expertise in differentiated academic teaching strategies, cognitive development, and behavior/classroom management, but often rely on other therapy professionals to meet the communication, and physical needs of their students with disabilities. Similarly, within their training, SLPs learn about a wide range of communication challenges, and strategies to improve language production, but are not always equipped to understand or work with the accompanying behavior and cognitive differences within this population of individuals with ASD.

The need for interdisciplinary training programs around ASD is clear when examining the competencies of recent graduates. In a survey of speech language pathologists (SLPs), respondents identified “autism” as the highest rated area in which greater focused graduate training was needed (Heilmann & Bertone, 2021). In the same survey, they identified individual education plans (IEPs) as the area of professional responsibility that new SLPs were most lacking. This suggests that SLPs are entering the field unprepared to work with individuals with ASD, and especially in establishing effective IEP goals for their clients. SLPs also report insufficient training on the use of alternative and augmentative communication (AAC), although there has been a recent increase in pre-service coursework on the topic (DeJarnette & Wegner, 2020). Given that communication challenges are a core requirement for the diagnosis of ASD (APA, 2013), and between 25-35% of individuals with autism are minimally verbal (Rose et al., 2016), it is imperative to ensure that SLPs are more familiar and confident in their skills and strategies for working with this population.

While SETs are also not often provided with interdisciplinary training exposure before they enter the workforce, they do sometimes receive training in collaboration. In a survey of 53 undergraduate teacher training programs in special education, 95% reported a collaboration course was required as part of the training program for SETs (McKenzie, 2009). However, in most of these courses (specific amount not specified), collaboration was not required in any field experiences. So, while pre-service SETs typically received training in collaboration, they were not often given opportunities to practice these skills before graduation.

Many existing programs for SLPs and SETs lack interdisciplinary training opportunities and remain entrenched in a single disciplinary training model. Training service providers to adopt a collaborative and inclusive approach in delivering services to students with special needs allows professionals to draw upon each others' expertise in more efficient and effective ways, and meet the more global needs of children who are struggling in multiple domains.

Interprofessional training programs that have been previously studied, show that effective models should provide opportunities for educational professionals to collaboratively troubleshoot problems and practice making data-based decisions (Hawkins et al., 2008). These models should include parallel or integrated coursework with shared competencies and instructional practices (McKenzie, 2009). However, university programs are not traditionally established in a way that allows integration across disciplines, and program competencies in each field are often intensively designed to establish focused expertise instead of broad understanding of the roles of other related professionals.

Following a model for evaluating program feasibility outlined by Teresi and colleagues (2022), this study examines the feasibility of one interdisciplinary model, the Interdisciplinary Multicultural Professional Autism Clinical Training (IMPACT) program using: 1) recruitment and 2) retention: looking at who this interdisciplinary program appealed to and their motivation and persistence to study; 3) fidelity: whether additional collaboration and interprofessional competencies were able to be added to existing master's degree programs in speech language pathology and special education and if students could complete all activities as designed; 4) acceptability: how scholars experienced the program and rated each of the program components, and 5) engagement: performance of scholars in program activities.

Interdisciplinary Multicultural Professional Autism Clinical Training (IMPACT) Program

The Interdisciplinary Multicultural Professional Autism Clinical Training (IMPACT) Program was developed with the support of grant funding from the Office of Special Education Programs (U.S. Department of Education) with the goal of training highly skilled, collaboratively trained practitioners who had the knowledge and tools to support children with ASD in their academic, social, speech, and language development through the application of evidence-based strategies. The program targets SLP and SET masters programs, and includes collaborative content, assessment, and applied learning opportunities between the two programs to better promote understanding of one another's roles and responsibilities, as well as opportunities to build on shared expertise in supporting students with multiple needs. Program activities were also built around the need to ensure that the addition of these competencies would not increase the time to degree completion.

Program Components

IMPACT includes four programmatic components on top of core degree requirements for SLPs and SETs: (1) Interdisciplinary Extension for Community Healthcare Outcomes (ECHO) Seminars, (2) three collaborative courses and assignments, (3) a community-based applied project grounded in evidence-based practices, and (4) collaborative clinical field experiences. These components were designed based on situated learning theory (Brown et al., 1989), which emphasizes learning through authentic experiences. It aimed to enhance students' understanding of evidence-based practices and their ability to gather practice-based evidence for assessing intervention effectiveness.

Interdisciplinary Extension for Community Healthcare Outcomes (ECHO) Seminars

ECHOs were first developed at the University of New Mexico to support the collaboration of medical professionals in support of patients with hepatitis C in rural and prison environments (Arora et al., 2007). Since then, the use of ECHOs has spread from healthcare settings across multiple fields, including education. Mazurek and colleagues (2017) piloted the use of the ECHO model for supporting individuals with ASD. The goal of ECHOs is to provide an online forum for professional cross-collaboration on a specific topic.

ECHOs are interdisciplinary online case-based collaborative seminars with related expert presentations. These sessions take place over Zoom in the evenings, and are attended by students, faculty, and community professionals. Each ECHO includes 10 minutes for introductions and orientation, 45 minutes for case presentation and discussion, 30 minutes for expert presentation, and 10 minutes for questions.

Collaborative Courses and Assignments

In addition to the approved program of study for each program, IMPACT scholars participate in three collaborative, concurrently-enrolled courses related to diverse children with ASD: Multicultural Issues, Current Research in Autism, and Assistive and Augmentative Communication (AAC). The syllabi for the courses were adjusted to facilitate cross-program collaboration and include collaborative signature assignments that required the use of research on evidence-based practices. In addition, all courses were moved to an online format, as the SET program was an exclusively online master's program. So, all collaborative activities were conducted online in both synchronous and asynchronous formats. See Table 1 for a brief description of the collaborative assignments designed to encourage collaborative communication and problem-solving by pairing students to work together across disciplines.

Applied Project

IMPACT scholars complete a supervised community-based project, involving research, resource creation, and interprofessional service delivery. Mentored by IMPACT faculty, students engage with

Table 1

IMPACT Collaborative Program Curriculum

Skill Focus	Assignment
Research	**Interdisciplinary Research Proposal:** Scholars were paired across disciplines and reviewed literature together and developed a hypothetical research study that incorporated both speech and teaching components for ASD students.
Collaboration	**Interdisciplinary Collaboration Map**: Scholars were paired across disciplines to create a paper that outlined concrete steps that they would take in the field to improve the likelihood of successful collaboration efforts and placement of students with ASD in the least restrictive environment. They identified the roles and responsibilities of each discipline and used existing research to outline two ways that those different professionals could effectively work together.
ASD Advocacy	**Bias Buster Paper:** Scholars were paired across disciplines and asked to identify two common biases against ASD students, and three concrete ways to address/combat those biases.
Collaborative Clinical Application	**Collaborative Case Consultation**: Cross-disciplinary scholar teams selected a case to work on together, and collect assessment data, review literature, develop and implement an intervention, and assess the efficacy of the intervention.
Research Application	**Applied Project Presentation**: Scholars presented their research or dissemination project to their colleagues for feedback, and provided peer review of the research methodology, evidence-base to support the intervention, and efficacy of the research project.

community partners to research and address a community-identified need. For example, those opting for research could conduct a single-subject or group-designed study to improve language skills or apply culturally appropriate testing. Scholars interested in training development could create culturally relevant materials on evidence-based practices for families or professionals, presented to community partners in both print and electronic formats. Projects are showcased at a research day at the end of each year.

Clinical Field Experiences

Scholars collaborate on solving individual clinical cases during their field experiences. They meet virtually every 2 weeks to present cases, receive feedback, and benefit from diverse perspectives and experiences. These collaborative discussions aim to enhance practical skills, deepen their understanding of their respective fields, and foster teamwork among specialists working with children with ASD. Scholars developed, implemented, and evaluated intensive, personalized evidence-based interventions for each case. They report their results in group consultations, providing data on targeted learning and developmental outcomes.

Program Feasibility

Recruitment

Applicant Demographics. IMPACT applicants were recruited through print and web information pages, as well as information sessions for the core degree programs. The program was advertised as an interdisciplinary training program focused on core interdisciplinary competencies to improve the provision of care to elementary-aged children with ASD within diverse communities. Applicants were invited to apply through an online application, which contained demographic questions, as well as questions about job history, prior education, and motivation to join the program. All participants had to be accepted to one of the participating university master's programs (SLP or Special Education, ASD), as well as the IMPACT program. A summary of applicant demographics is shown in Table 2.

The overall demographics of applicants were reflective of the education professional demographics nationwide, where most teachers are white females (National Center for Education Statistics, 2023). As shown in Table 2, IMPACT applicants were typically female (85.7%), white (97.1%), non-disabled (90%), non-English language learners (91.2%), however, nearly half were bilingual or multilingual (54.8%). Selected scholars (*n*=16) were similar in demographics to the larger applicant sample; however, there was an intentional effort to include racial, linguistic and gender diversity amongst the scholars, so there is a slightly higher rate of males, non-white, and bilingual scholars included. Nevertheless, there is potential for bias in this sample, due to the electronic method of application, as well as the requirement for applicants to be admitted to the university at large, which may limit participation from low-SES and/or academically disadvantaged students.

Motivation for Study. All applicants were asked to write a brief, 300-word essay on their future career goals upon program completion. Each essay response was coded to identify applicants' primary motivations for joining this project. Grounded theory was used to guide the analysis process using open and axial coding to develop codes, concepts, categories, and ultimately themes (Glaser & Strauss, 2017). Applicants (*n*=35) reported many motivations for applying (see Table 3). Since applicants could list multiple motivations within their essays, there is overlap in frequency of some of the themes. The vast majority of applicants (97.1%; *n*=34) had experience with individuals with ASD prior to applying, with 82.9% (*n*=29) having prior work experience in the field, and 14.3% (*n*=5) having a family member or close friend with ASD.

The most commonly reported motivation for program application was personal fulfillment (88.57%). Themes in this category included a personal desire for progress or goal attainment. As an example, one applicant stated, "I am most enthusiastic

Table 2

IMPACT Applicant Demographics

		All Applicants *N* = 35	Admitted Scholars *N* = 16
		% (*n*)	% (*n*)
Gender	Male	14.3 (5)	18.8 (3)
	Female	85.7 (30)	81.3 (13)
Latino	Latino	28.6 (10)	31.3 (5)
	Non-Latino	71.4 (25)	68.8 (11)
Race	White	97.1 (34)	90.9 (15)
	Black	2.9 (1)	9.1 (1)
Bilingual/ Multilingual	Yes	54.8 (14)	62.5 (10)
	No	45.2 (17)	37.5 (6)
Disability	Yes	10 (2)	9.9 (1)
	No	90 (20)	90.1 (10)
ELL	Yes	8.8 (3)	13.3 (2)
	No	91.2 (31)	86.7 (13)

Table 3

IMPACT Applicant Motivation for Applying

Motivation	*n*	%
Personal fulfillment	31	88.57%
Supporting Children	15	42.86%
Advocacy	11	31.43%
Professional Advancement	10	28.57%
Witnessed Inequity or Need	7	20.00%

about the opportunities to apply my ideas and experiences in clinical settings to…become a speech-language pathologist with a diverse set of talents, capable of empowering others."

The second most highly reported motivation was that the applicant wanted to work in support of children/students with special needs (42.86%). Themes in this category included the desire to gain skills and strategies, improve learning and communication outcomes, and impact childrens' lives. An applicant stated, "I want to expand my understanding and knowledge of autism so that I can provide more support for my students and their families."

Applicants also indicated a desire to advocate for a specific subset or community of learners (31.43%). Communities specifically mentioned were the Hispanic community, bilingual learners, the Deaf community, and the ASD community. One applicant said, "Being Hispanic, I also feel there is a community who may need help but do not know where to ask due to language barrier or cultural differences." Another applicant stated, "In meeting with a few D/HH [deaf/hard of hearing] speech-language pathologists, I have learned that many professionals that work with this community do not have the skills to work with such individuals, including not knowing enough sign language."

Similarly, some applicants mentioned that they were inspired to apply when witnessing an inequity or need that they felt compelled to work to rectify (20%). These inequities sometimes identified certain communities, as discussed above, interactions with specific individuals, or reflections on systems as a whole. One applicant stated, "I saw how these school districts and the resources available were limited due to the overwhelming caseloads and therefore, their inability to provide enough support to every student. This unfortunate reality is part of why I'm pursuing my career as an SLP."

Finally, applicants indicated professional advancement as motivation (28.57%). These essays mentioned certification goals, expanding their professional knowledge, and obtaining future jobs in the field.

Retention

Out of the 35 applicants, 16 scholars were selected to take part in the IMPACT program, with three cohorts of five to six scholars in each cohort. Scholars received stipends for at least 50% of their master's program tuition, and there was no additional cost to take part in the IMPACT program activities. There was high retention of scholars, with 15/16 (93.8%) remaining in the program. The one scholar who left the program was enrolled but decided not to participate after signing the contract for the project, but before initiating any program activities. This scholar reported feeling overwhelmed at beginning the master's program, while concurrently starting a new teaching career in the same semester, and chose to leave the IMPACT program to avoid additional activities and responsibilities at that time. This decision was not based, however, on impressions of the program in practice though, as no activities had been completed. Two cohorts (*n*=10) have completed all program activities, and the third cohort (*n*=5) is halfway through the 2-year program.

Fidelity

Fidelity to the program included the percent of program activity completion by participants. IMPACT specific activities (outlined in detail above) included four components for each scholar, 1) attending ECHO seminars, 2) completing collaborative coursework and assignments, 3) interdisciplinary field experience, and 4) an applied project. Scholar attendance at ECHO seminars was high at 93.7% (164/175), with coursework completion even higher at 98.3% (59/60 activities completed). Field experiences and applied projects both had 100% completion rates. All participating scholars (not including the one scholar who left the program prior to initiating activities) have completed all program activities, apart from one scholar who did not complete one collaborative assignment. These requirements were above and beyond their original degree program requirements, and both of the first two cohorts (*n*=10, 100%) were able to complete and successfully graduate with their master's degree. Thus, there was very high fidelity to the program, as it was designed.

Acceptability

Another important component of program feasibility is acceptability of the program by those who participate. Scholars rated each of their program experiences independently, and all activities were considered valuable and of high-quality. Acceptability ratings for each program component is described below.

ECHO. There were 20 ECHO sessions offered over the course of the program, and at the conclusion of each ECHO, participants were asked to complete a voluntary survey regarding their opinions on the ECHO topic, speaker, session objectives, and learning outcomes. Overall satisfaction was high across all sessions (*M*=4.73, *SD*=0.17); on a five-point scale where 1- Extremely unsatisfied, 2- Unsatisfied, 3- Neutral, 4- Satisfied, and 5- Extremely satisfied). The sessions scoring highest in satisfaction were *Inclusive Language* and *Interprofessional Case Study: ASD* (*M*=5.0, *SD*=0), *Social Inclusion of Children with ASD in Schools* (*M*=4.86, *SD*=0.38) and *Parent Perspectives of Disabilities* (*M*=4.86, *SD*=0.38). Across all sessions, 97.35% of participants rated their overall satisfaction as satisfied or extremely satisfied.

Participants agreed that sessions increased their ability to work at the top of their scope of practice (*M*=4.52, *SD*=0.29); on a five-point scale where 1- Strongly disagree, 2- Disagree, 3- Neither agree nor disagree, 4- Agree, and 5- Strongly agree. The sessions scoring highest in professional impact were *Inclusive Language (M*=5.0, *SD*=0), *Social Inclusion of Children with ASD in Schools* (*M*=4.86, *SD*=0.36) and *Alternative Perspectives in Stuttering Intervention* (*M*=4.86, *SD*=0.38). Across all sessions, 96.69% of participants agreed or strongly agreed that the session content was related to their scope of practice.

Participants also strongly agreed that sessions fostered valuable collaboration among professionals with shared job responsibilities and interests (*M*=4.79, *SD*=0.15); on a five-point scale where 1- Strongly disagree, 2- Disagree, 3- Neither agree nor disagree, 4- Agree, and 5- Strongly agree. The three highest scoring sessions received a score of 5.0 (*SD*=0): *Inclusive Language, Parent Perspective of Disabilities,* and *Interprofessional Case Study: ASD*. Overall, 94.1% of respondents agreed or strongly agreed that the sessions fostered collaboration. These ratings suggest that ECHOs were valued by participants and effectively prepared participants to support individuals with ASD.

Collaborative Coursework (including the Applied Project). For all collaborative courses, including the applied project course experience, scholars were asked to rate key aspects about the delivery and accessibility of content. Overall, courses were highly rated, as scholars indicated that the coursework was relevant (100.0%), appropriately challenging (83.0%), required a reasonable amount of effort (91.7%) and that class time was used efficiently (75.0%). When asked to comment on opportunities for improvement, scholars indicated that they wanted "additional information on specific interventions" and "more foundation of key vocabulary across disciplines." Additionally, they asked for "more specific rubric guidelines for assignments." Finally, some students expressed difficulty navigating interdisciplinary collaboration, stating, "Working with my partner was hard. I don't like conflict." However, scholars also suggested that the courses were a valuable addition to their degree programs. For example, one scholar wrote, "Learning about AAC was invaluable. I never would have understood the broad scope of what it was without this class."

Field Experiences. Scholars completed independent field experiences and engaged in collaborative case consultation to discuss challenges and engage in team problem-solving. All scholars who have completed the field experience (*n*=10; 100%) reported that the consultation process was helpful in considering aspects of the case that they had not previously considered. The majority (*n*=8; 80.0%) also reported having learned about a new strategy or option as a result of their discussions. There was very high satisfaction with the collaborative case consultation process, and they felt that this was an important activity for all students within their respective degree programs.

Engagement

ECHO. ECHO sessions were offered on a wide variety of topics related to ASD, such as apraxia, executive function, parent perspectives, inclusive language, and bilingualism. In addition to IMPACT scholars, faculty, students in multiple related programs, and community members were all invited to join ECHO seminars to increase the interdisciplinary nature of the discussions. On average, ECHOs were attended by 28.39 participants (*SD*=7.11), with a mean of 5.83 faculty, 13.22 students, and 8.39 community professionals. *Sex Differences in Brain Patterns and Autism* was the most highly attended topic (42 attendees). There was a very high rate of attendance at ECHO seminars by scholars, with 97.0% of sessions attended.

Collaborative Courses and Assignments. Scholars performed well across courses and collaborative assignments. All students in the first two cohorts (*n*=10) were able to complete their primary degree program successfully, and the third cohort (*n*=5) is on track with all coursework and program activities. Across the three collaborative courses (Multicultural Issues, Current Research in Autism, and AAC), 83% of all students have received an A grade. No scholars have received below a B grade in any course, showing mastery of content by the end of each class. Scholars have also completed collaborative assignments successfully, with a mean score of 94.3% (*SD*=7.5). Their assignments showed depth in analysis and integration of expertise and interests across disciplines. Scholars also performed well in their applied projects course, in which all scholars (100%; *n*=10) have received an A grade and were able to produce a wide variety of research and dissemination projects.

Field Placement. Finally, participants were rated on their clinical skills within field placements. The university supervisor used goal attainment scaling (GAS) to measure intervention success; GAS scores can range from -2 to +2, where scores above 0 indicate better than expected outcomes (Kiresuk & Sherman, 1968). This data was compiled after each field experience to evaluate the scholars' impact on student progress. Overall, 90% (9/10) of scholars obtained a +1 or higher, indicating positive engagement and impact on the clients that they worked with in the field.

Discussion

The IMPACT program was developed to provide collaborative, interdisciplinary training around ASD to both SLP and SET masters students on top of their original degree programs. Through ECHO seminars, collaborative coursework, applied projects and field experiences, IMPACT provided graduate students with opportunities to learn about each other's professions, skills and strategies, and practice collaboration and team problem-solving before joining the field. The five markers of program feasibility (recruitment, retention, fidelity, acceptability, and engagement; Teresi et al., 2022) suggest that the program is feasible, as there was a high demand for the program from a diverse pool of motivated applicants, and those who were accepted have stayed engaged and completed all program activities, as designed. Program activities were also highly rated by the scholar and scholars were successful at mastering material and felt prepared to engage in collaborative professional activities around ASD as a result of the additional competencies addressed.

Program Feasibility Considerations

Recruitment and Retention. A key measure of feasibility of the project was being able to recruit students to join, and understanding the type of student who would be interested in this interdisciplinary training program. Given the diverse population of students being served, this was also an opportunity to recruit scholars who better represented the wide range of students in our schools. Currently the US student population is 48.1% white and 48.6% female (U.S. Census Bureau, 2021), whereas SETs are approximately 79.8% white and 85.4% female (Data USA, 2023), and the SLPs are approximately 92% white and 96% female (American Speech-Language-Hearing Association [ASHA], 2019). IMPACT scholars were still majority white and female (90.9% white and 81.3% female), however, grant funding allowed scholars to overcome financial barriers to obtaining a master's degree, and increase the diversity of the cohorts within these two fields. Retention in the program (93.8%) was also extremely high, showing the feasibility of completing the program concurrently with their original degree program.

Scholars were predominantly motivated to study ASD for personal reasons, including having a family member or close friend with ASD (14.3%) or having worked previously in the field (82.9%). Family members are uniquely poised to understand the challenges around ASD within the community, and to most comprehensively support their family members who may be struggling. Having this personal connection to ASD was considered a strength of potential applicants, and at least one member of each cohort (3/16 scholars; 18.8% overall) was a family member of an individual with ASD and was able to share this unique perspective during clinical case discussions.

Program Fidelity. There was a high rate of completion of all program activities, on top of the scholar's original degree program requirements. The program was carefully designed to align program activities around existing requirements. Creating an IPE program required first ensuring institutional support for the implementation of a cross-disciplinary program. The two targeted degree programs for SETs and SLPs had to be flexible to align program activities within existing degree requirements, especially without extending the time to graduation. Administration, faculty and staff were asked to consider multiple models and adapt existing advising protocols and degree sequences to allow for a small subset of scholars to test this program.

One of the unique challenges to this program was in combining an in-person with an online master's program for shared program activities. Since the online SET students were recruited from across the U.S., all program components had to be offered in the online environment. This was an adjustment for the SLP program, where all collaborative courses had to be translated into the online format. However, the collaborative courses were highly rated by scholars, and both in-person and online students reported feeling that the courses allowed them to interact successfully and learn from one another.

Program Acceptability. A key component of program evaluation was the frequency and varied sources of program feedback that were solicited. For each component of the IMPACT program (collaborative courses, ECHO seminars, and applied project and field experiences), scholars were asked to rate and discuss their experiences. Outside evaluations were also sought to provide information for program improvements. All attendees of ECHO seminars rated the sessions, in addition to program scholars. This broader evaluation allowed continual adjustments to be made to the program, and the development of additional resources when scholars were struggling.

Program feedback suggested that students initially struggled with cross-discipline collaboration when they did not first share similar foundational knowledge, such as a common vocabulary through which to discuss ideas. In response to this challenge, a glossary of terms was developed in which all scholars could contribute, and program faculty would both define and give examples of the terms as a reference for students throughout the program and after graduation. This glossary also helped identify areas where foundational discipline-specific knowledge was needed to ensure comprehension in shared collaborative courses.

Program Engagement. All scholars were able to perform well within their coursework and produce high-quality collaborative assignments that were relevant to both professions. A common challenge to IPE has traditionally been in merging the different perspectives and strategies of professionals in collaborative practices. In a recent systematic review of collaboration, Griffiths and colleagues (2021) highlighted that while collaboration is considered a best practice in schools, team members may struggle with differing priorities and perspectives, training backgrounds, or perceptions of roles and responsibilities. The authors noted that there can even be a fundamental lack of agreement on what collaboration means. They present a conceptual model of collaboration, which emphasizes the building blocks of relationship building, shared values, and active participation, as well highlighting the need for clear feedback loops and individual accountability (Griffiths et al., 2021). While this model highlights best practices in theory, the applied practice of collaboration is necessary within training if we want professionals to collaborate in the field. IMPACT scholars did struggle at times with the interpersonal demands of collaborative assignments. However, the high-quality products that resulted from resolving those conflicts, negotiating differing perspectives and valuing each other's areas of expertise show that those difficulties can be overcome effectively at the pre-professional level.

Implications and Future Directions

The findings from this evaluation provide several important implications. First, applicants are drawn to programs focused on ASD for a variety of reasons. Understanding these motivations may increase program retention and student engagement. Knowing this, IPE program developers should work to align program components and recruitment efforts with candidates' goals. Additionally, because most applicants had prior experiences with individuals with ASD, it may be beneficial to find ways to leverage these existing experiences and recruit students into autism programs who have this foundational knowledge to share with their colleagues.

The IMPACT program model was found to have high fidelity, acceptability, and engagement. As such, this model demonstrates that such programs can be effectively implemented without overburdening students, while still providing pre-service teachers and SLPs with valuable learning about ASD and professional collaboration. Because cross-disciplinary collaboration did have initial challenges, it is important that future programs are proactive in planning for these potential roadblocks.

While initial evaluation suggests that this program provides a feasible outline for IPE around ASD, future research may be oriented around the long-term effects of such training programs, and in what ways practitioners who participated in IPE programs are actually more collaborative in the field. Future programs should also consider the extension of this model to include additional types of professionals, such as occupational therapists, school psychologists, and behavior analysts. Finally, while the study identified key motivations for applying to the program, future research could explore barriers to application and participation, which may help increase accessibility and inclusivity.

Conclusion

Given the complex needs of individuals with ASD, all professionals need to be able to communicate and collaborate within their practice to support the needs of this population most comprehensively. The IMPACT program was developed to teach these collaboration skills within the professional training of SET and SLP masters students. IMPACT was found to be feasible in preparing scholars for collaboration in clinical practice around ASD. While IPE programs may support early career professionals in establishing themselves as valuable team leaders, these programs must be intentionally designed with flexible institutional support to ensure that all degree requirements and collaborative activities can be offered synergistically. Given the evidence supporting collaborative practice in the field, it is critical that more programs are able to fully integrate interdisciplinary collaboration opportunities in their professional training.

References

American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

American Speech-Hearing Association (ASHA). (2019). A demographic snapshot of SLPs. *The ASHA Leader*. https://doi.org/10.1044/leader.AAG.24072019.32

Arora, S., Thornton, K., Jenkusky, S. M., Parish, B., & Scaletti, J. V. (2007). Project ECHO:Linking university specialists with rural and prison-based clinicians to improve care for people with chronic hepatitis C in New Mexico. *Public Health Reports, 122*(2), 74-77.

Barr, H., Koppel, I., Reeves, S., Hammick, M., & Freeth, D. (2005). *Effective Interprofessional Education*. Blackwell. https://onlinelibrary.wiley.com/doi/book/10.1002/9780470776445

Brown, J. S., Collins, A., & Duguid, P. (1989). Situated cognition and the culture of learning. *Educational Researcher, 18*(1), 32-42.

Centers for Disease Control and Prevention. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years. Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *Morbidity and Mortality Weekly Report Surveillance Summaries 2023, 72*(No. SS-2), 1–14.

Data USA. (2023, March 13). *Special education teachers*. https://datausa.io/profile/soc/special-education-teachers#:~:text=The%20workforce%20of%20Special%20education,Special%20education%20teachers%20is%20White

DeJarnette, K., & Wegner, J. (2020). Preservice education in augmentative and alternative communication: An update. *Perspectives of the ASHA Special Interest Groups, 5*(5), 1243–1261. https://doi.org/10.1044/2020_PERSP-19-00154

DuFour, R. (2007). Professional learning communities: A bandwagon, an idea worth considering, or our best hope for high levels of learning? *Middle School Journal, 39*(1), 4–8.

Glaser, B., & Strauss, A. (2017). *Discovery of grounded theory: Strategies for qualitative research*. Routledge.

Griffiths, A.-J., Alsip, J., Hart, S. R., Round, R. L., & Brady, J. (2021). Together we can do so much: A systematic review and conceptual framework of collaboration in schools. *Canadian Journal of School Psychology, 36*(1), 59-85.

Hattie, J. (2008). *Visible learning: A synthesis of over 800 meta-analyses relating to achievement*. Routledge.

Hawkins, R. O., Kroeger, S. D., Musti-Rao, S., Barnett, D. W., & Ward, J. E.

(2008). Preservice training in response to intervention: Learning by doing an interdisciplinary field experience. *Psychology in the Schools, 45*(8), 745–762.

Heilman, J., & Bartone, A. (2021). Identification of gaps in training, research, and school-based practice: A survey of school-based speech-language pathologists. *Language, Speech, and Hearing in Schools, 52*(4), 1061-1079.

Hsiao, Y.-J., & Sorensen Petersen, S. (2019). Evidence-based practices provided in teacher education and in-service training programs for special education teachers of students with autism spectrum disorders. *Teacher Education and Special Education, 42*(3), 193-208. https://doi.org.ezproxy1.lib.asu.edu/10.1177/0888406418758464

Individuals With Disabilities Education Improvement Act of 2004. 20 U.S.C. 1414(d)(1)(B) (2006).

Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal, 4*(6), 443-453.

McKenzie, R. G. (2009). A national survey of pre-service preparation for collaboration. *Teacher Education and Special Education, 32*(4), 379-393.

Mazurek, M. O., Crispel, O., & Kasperski, R. (2017). The impact of teacher training in special education on the implementation of inclusion in mainstream classrooms. *International Journal of Inclusive Education, 25*(9), 1079-1090.

McLeskey, J., Barringer, M.-D., Billingsley, B., Brownell, M., Jackson, D., Kennedy, M., Lewis, T., Maheady, L., Rodriguez, J., Scheeler, M. C., Winn, J., & Ziegler, D. (2017). *High-leverage practices in special education*. Council for Exceptional Children & CEEDAR Center.

National Center for Education Statistics. (2023). *Characteristics of public school teachers*. Condition of education. U.S. Department of Education, Institute of Education Sciences. https://nces.ed.gov/programs/coe/indicator/clr.

Nunez, L. (2015). Achieving Quality and Improved Outcomes Through Interprofessional Collaboration. ASHA Leader Live.

Pfeiffer, D., Pavelko, S., Hahs-Vaughn, D., & Duddinge, C. (2019). A national survey of speech-language pathologists' engagement in interprofessional collaborative practice in schools: Identifying predictive factors and barriers to implementation. *Language, Speech, and Hearing Services in Schools, 50*(4), 639–655.

Rose, V., Trembath, D., Keen, D., & Paynter, J. (2016). The proportion of minimally verbal children with autism spectrum disorder in a community-based early intervention programme. *Journal of Intellectual Disability Research: JIDR*, *60*(5), 464–477. https://doi.org/10.1111/jir.12284

Shoffner, M., & Wachter Morris, C. A. (2010). Preparing preservice English teachers and school counselor interns for future collaboration. Teaching Education, 21(2), 185–197.

Teresi, J. A., Yu, X., Stewart, A. L., & Hays, R. D. (2022). Guidelines for designing and evaluating feasibility pilot studies. *Medical Care, 60*(1), 95–103. https://doi.org/10.1097/MLR.0000000000001664

U.S. Census Bureau. (2021). *American Community Survey, 1-year estimates*. www.census.gov/acs.

U.S. Department of Education. (2022). Fact sheet: The U.S. Department of Education announces partnerships across states, school districts, and colleges of education to meet secretary Cardona’s call to action to address the teacher shortage. https://www.ed.gov/coronavirus/factsheets/teacher-shortage.

Zablotsky, B., Black, L. I., & Blumberg, S. J. (2019). Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2017–2018. *MMWR Surveillance Summaries, 68*(5), 1–12. https://pubmed.ncbi.nlm.nih.gov/29235982/

This work was supported by the Office of Special Education Programs, US Department of Education: H325K210006. Correspondence concerning this article should be addressed to Erin Rotheram-Fuller, Educational Leadership and Innovation, Arizona State University, PO Box 871811, Mail Code 1811, Tempe, AZ 85287-1811. E-mail: erf@asu.edu

Let Grow: Supporting Parents of Students with Intellectual Disability in Inclusive Higher Education Programs

Betty S. Patten, Claire C. Hebert, Jessica H. Milton, and Christine Drew[1]
Auburn University

Abstract: Inclusive Postsecondary Education (IPSE) programs offer students with intellectual disability (ID) and their parents or guardians opportunities for growth and increased independence. Understanding parent and guardian perspectives is essential to enhance communication, engagement, and support mechanisms within these programs. This paper examines the dynamic roles of parents and guardians in supporting individuals with intellectual disability in an IPSE program and aims to inform the development of support as parents/guardians transition from the caregiver role to the natural support role. This manuscript discusses a range of intervention strategies for parents/guardians that were implemented following a comprehensive program evaluation, including feedback from all stakeholders, particularly the insights of parents and guardians. These strategies span from broad system-centered supports to more specific, person-centered approaches tailored to meet the diverse needs of families and the unique needs of students. The paper provides an overview of six strategies implemented within an IPSE program in the southeast United States that promote communication and collaboration. The strategies offered facilitates a scaffolded support system for parents and guardians, embodying a "let grow" philosophy that encourages student autonomy and supports achieving the program's objectives for its students to achieve their goals of independence.

In the dynamic landscape of inclusive postsecondary education (IPSE) programs, understanding the perspectives of all stakeholders is paramount for fostering effective communication, engagement, and support structures. The IPSE program discussed in this article is designed to support young adults with intellectual disability through an inclusive postsecondary program across five pillars: academics, daily living skills, employment, personal/social skills, and health and wellness. The IPSE program described in the paper offers a residential four-year comprehensive transition program. As of 2024, the IPSE program is currently in its sixth year of operation, has seven full-time staff members, one part-time employee, six graduate assistants, and a total current enrollment of 27 students across four cohorts. At the time of the program evaluation discussed in this article in 2022, the program had four full-time staff members, and was in its fourth year with 24 students across four cohorts. However, like any program in its infancy and as it matures, it has faced unique challenges and opportunities for growth, particularly in family engagement and communication. Outcomes from the IPSE program's 2022 program evaluation reported parents and guardians as stakeholders in the program desired more opportunities for communication with one another, and with program staff (Hebert & Patten, 2024). In efforts to meet the desires reported by parents and guardians from the 2022 program evaluation, the IPSE program implemented the six intervention strategies discussed in this manuscript. This paper extends beyond initial insights, undertaking a comprehensive literature review. It aims to situate the findings of the program evaluation within the broader context of academic research, identifying parallels and divergences in the experiences and expectations of parents and guardians in secondary versus postsecondary programs.

Additionally, Think College's most recent annual report of the cohort 3 Transition and Postsecondary Programs for Students with Intellectual Disability (TPSID) model demonstration project, identified strengthening communication between programs and families around levels of support, expectations, and supervision within the program as a relevant topic in the field driving support structures moving forward (Grigal et al., 2024).

A key focus of this manuscript is to provide a detailed overview of the various supports resulting from intervention strategies listed that are available to parents and guardians within the IPSE program discussed in this article that arose from a program evaluation. This examination will highlight how these supports are designed to meet the unique needs of families as they navigate the often-complex landscape of IPSE, where the primary goal is to help increase the independence and autonomy of students enrolled. By exploring these intervention strategies, the authors seek to understand how the strategies they implemented contribute to the overall effectiveness of the program's support to collaborate with families involved while promoting autonomy.

Additionally, this paper describes the evolving roles of parents and guardians as their young adults transition from high school to IPSE programs. This transition often involves significant changes in the level of involvement and types of support required from families (Wehman, 2007). Understanding these changing dynamics of transitioning from secondary education to postsecondary education is crucial for developing effective communication strategies and support mechanisms within IPSE programs given that the required communication outlined in the Individuals with Disabilities Act (2004) state teachers in the elementary through high school setting are legally required to communicate with parents or guardians.

Moreover, the study reviews the implementation of system-centered intervention strategies to more personalized, person-centered intervention strategies. This analysis will provide insights into how IPSE programs, like the one discussed in this article, can tailor their support systems to address individual students' and their families' diverse needs and preferences. The goal is to identify practices and strategies that can be generalized to other programs while respecting each family's unique circumstances. To view demographic information for the parents and guardians discussed in this article who are supporting a young adult in the IPSE program discussed in this paper, see Table 1.

In sum, this paper aims to explore these multifaceted aspects of parental engagement and communication within this IPSE program in the southeastern US. By examining parents' perspectives, this study contributes to a deeper understanding of families' integral role in the success of students enrolled in IPSE programs and the importance of fostering effective communication and collaborative relationships among all stakeholders. Through a literature review, program analysis, and exploration of evolving parental roles, this paper offers valuable insights and recommendations for enhancing family engagement in IPSE programs.

Changing Roles of Parents/Guardians

The transition from high school to postsecondary education represents a significant shift in the roles and rights of parents and guardians of students with Intellectual Disabilities (Morningstar et al., 1995). Two pivotal pieces of legislation frame this change: The Individuals with

Table 1

2023-2024 Parent/Guardian Demographics

	n	%
Gender		
Female	25	52%
Male	23	48%
Ethnicity		
White	42	79%
Black	6	12%

Note. n = 48

Disabilities Education Act (2004) and the Higher Education Opportunity Act (2008).

High School under the Individuals with Disabilities Education Act of 2004

Section 300.322 of the Individuals with Disabilities Education Act (2004) provided a strong foundation for parental involvement in the educational journey of children with intellectual disability. Under the Individuals with Disabilities Education Act (2004), parents have extensive rights, including the right to request an evaluation of their child, the right to request a re-evaluation at any time, and the right to be part of the team that decides on the special education services and therapies their child will receive.

In the high school setting, parents can assume a leadership role in their child's education. They act as decision-makers and advocates, taking the "driver's seat" in navigating the educational system to ensure their child receives the free and appropriate support and services to succeed (MAC Stuff, 2001). This involvement is crucial, as it allows for tailored educational plans that cater to the student's individual needs (MAC Stuff, 2001).

Additionally, guardianship considerations and the transfer of rights at the age of majority play a critical role (PACER, 2015). This legal transition requires parents and guardians to reassess their roles and the extent of their involvement in their child's education (PACER, 2015). It serves as a time that signifies to the student that they become their guardian, at the same time as a traditional undergraduate student at university (PACER, 2015).

Transition to College under the Higher Education Opportunity Act of 2008

The enactment of the Higher Education Opportunity Act (2008) marked a significant shift towards inclusivity in postsecondary education for students with Intellectual Disabilities. This act reauthorized the Higher Education Act of 1965, introducing provisions to improve access to postsecondary education for this demographic (Madaus et al., 2012). Notably, the Higher Education Opportunity Act (2008) made federal student aid available to students with Intellectual Disabilities for the first time and established comprehensive transition and postsecondary programs specifically designed for them (Lee, 2009).

Under the Higher Education Opportunity Act (2008), the role of parents evolves from being the primary decision-maker to a valued team member (Madaus et al., 2012; Stinnett et al., 2023). While they may not hold guardianship in the same capacity as during the high school years, their role shifts towards that of a consultant or advocate alongside their child (Madaus et al., 2012; Stinnett et al., 2023). This change is partly due to the Family Educational Rights and Privacy Act (1974) laws, which limit parental access to educational records without explicit consent from the student.

The Higher Education Opportunity Act (2008) underscores the importance of students with intellectual disabilities having access to and the support necessary for success in postsecondary education. It recognizes the role of family as crucial yet fundamentally different from their role in K-12 education. Parents and guardians are encouraged to support their children's independence and self-advocacy skills, necessary for navigating the challenges and opportunities of higher education (Madaus et al., 2012).

The transition from the Individuals with Disabilities Education Act (2004) to the Higher Education Opportunity Act (2008) represents a paradigm shift in how the educational system views and supports students with intellectual disability and their families. Moving from a highly involved, decision-making role in high school to a more consultative role in college, parents and guardians are essential to this journey, yet is often much easier said than done. These changes reflect a broader commitment to inclusivity and accessibility in education, ensuring that students with Intellectual Disabilities can pursue higher education and achieve their full potential (Madaus et al., 2012).

As students transition from high school to postsecondary education, the shift in parental roles from primary decision-makers to more of a supportive, consultative position is a natural progression for many families (MAC Stuff, 2001). This transition mirrors the journey of their typical peers, emphasizing independence and self-advocacy for young adults. However, it is essential to acknowledge that for parents and guardians of students with intellectual disability, this shift can present unique challenges and may be met with resistance (MAC Stuff, 2001).

Recognizing the need for continued support, families of students with intellectual disability should be provided with resources and guidance to navigate this new phase. The transition can evoke emotions as parents adapt to their evolving role while striving to ensure their child's educational and developmental needs are met in a postsecondary environment (Miller et al., 2018).

Transitioning to new settings and environments, and fading of supports, highlights the importance of targeted support programs for families to facilitate a smooth transition. These programs can offer education on legal and procedural changes, such as those outlined in the Individuals with Disabilities Education Act (2004) and the Higher Education Opportunity Act (2008), and provide strategies for effective advocacy in a postsecondary setting. Additionally, they can serve as a platform for parents to connect with and learn from the experiences of other families navigating similar changes. "Letting go" and allowing young adults to grow and explore their independence is a critical step in their development so that students learn through experiencing the success and failures that are a natural part of life (Virginia Commonwealth University, 2021). However, for a transition to be successful, parents and guardians need access to support systems that can help them understand their new roles, address their concerns, and ultimately embrace the opportunities that inclusive postsecondary education offers their children (Miller et al., 2018).

In summary, while the transition to postsecondary education is a natural step towards independence for young adults, including those with intellectual disability, it necessitates a supportive framework for families. Providing the necessary tools and resources has suggested to ease this transition, reduce resistance, and ensure a positive and enriching experience for students and their families (Hebert & Patten, 2024).

Implementation of Intervention Strategies

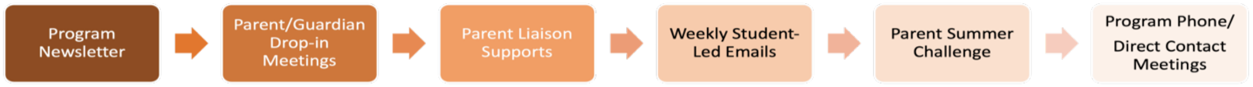
Both student-focused planning involving student participation (i.e., person-centered planning) and family engagement, involvement, and empowerment stand as two of the five critical components to supporting students as they transition to college, along with student development, interagency collaboration, and program structures (Kohler et al., 2016). Prior literature also reports that although the student becomes the primary advocate for themselves as they transition to college upon reaching the age of majority, parent attitudes and expectations will continue to shape the experiences and outcomes of their young adult while enrolled in IPSE programs (Agarwal et al., 2021; Foley et al., 2012; Grigal et al., 2014; Merel et al., 2022; Stinnett et al., 2023). Additionally, Think College's 2021 Accreditation Standards for IPSE mention the role of parents nine times (Think College National Coordinating Center Accreditation Workgroup, 2021), highlighting the ongoing importance of viewing parents/guardians as essential members of a student's support team in IPSE programs even with their role evolving to emphasize autonomy of their young adult.

To honor the evidenced-based practice highlighting person-centered planning for young adults' transition to college (Kohler et al., 2016), as well as to best utilize resources such as time and funding available to continue to center day-to-day student services on campus, the IPSE program discussed in this article implements a mixture of both system-centered and person-centered approaches to parents/guardians as members of their young adult's support team. This includes intervention strategies such as 1) a bi-monthly program newsletter, 2) parent/guardian drop-in meetings, 3) parent liaison support, 4) weekly student-led emails, 5) Parent Summer Challenge, and 6) contact by program phone and direct contact meetings. This programming primarily takes place via telephone or digitally using platforms such as Zoom™, Microsoft Outlook™, Box™, and Smore™ newsletter platform to accommodate parents/guardians that may work during weekdays and live out of town/out of state and would be otherwise unable to attend campus in-person to receive these intervention strategies. An overview of the IPSE program intervention strategies discussed in this manuscript can be found in Figure 1, with interventions spanning from system-centered intervention strategies on the left to person-centered on the right. See Table 2 for an overview of parent/guardian distances in location from the IPSE program discussed in this article.

System-Centered Approaches

While it is important to view parent/guardian involvement as a valuable resource and crucial factor when it comes to determining student success post-IPSE program involvement (Agarwal et al., 2021; Foley et

Figure 1: IPSE Program Parent/Guardian Intervention Strategies



Note. Supports are listed from most system-centered intervention strategies (left) to most person-centered intervention strategies (right)

Table 2
2023-2024 Parent/Guardian Distance from Program

	n	%
0 – 100 miles	20	42%
100 – 200 miles	24	50%
200 – 300 miles	0	0%
300 – 400 miles	0	0%
400 – 500 miles	0	0%
500 – 600 miles	0	0%
600 – 700 miles	0	0%
700 – 800 miles	2	4%
800 – 900 miles	0	0%
900 – 1,000 miles	0	0%
>1,000 miles	2	4%

Note. n = 48

al., 2012; Grigal et al., 2014; Merel et al., 2022; Stinnett et al., 2023), it is also worth considering the resources required to support parents/guardians as their young adult transitions into college, continues throughout their time in college, and then transitions out of college. Additionally, it is important to note that many students in IPSE programs will need intermittent support throughout their adult life and in many cases that will come from a parent/guardian. The more interventions that occur for parents/guardians, specifically in IPSE programs, the more time and funding are needed. For many programs, this leaves staff deciding between using time to support parents/guardians or students on campus during weekday working hours (Hebert & Patten, 2024). As a result, the IPSE program discussed in this article aimed to streamline some forms of communication with parents/guardians in a routine manner that both allows parents/guardians to remain informed of programmatic updates and parents/guardians to connect without taking instructional time or individualized support time away from students, such as implementing a bi-monthly program newsletter, hosting monthly parent/guardian drop-in meetings, and appointing parent liaison representatives who act as external support from IPSE program staff for additional parent/guardian support.

To best prepare students and their parents/guardians for life after the program, it is essential that programs consider how to gradually reduce the level of support provided, fostering greater independence and self-reliance. However, consistent updates and communication remain vital while they are still part of the program.

Program Newsletter

Description of Intervention

The southeastern IPSE program discussed in this article offers a bi-monthly newsletter to current families, students, and stakeholders (i.e. university instructors, peer mentors, donors). This carefully curated approach is designed to keep families, the local community, and the campus community informed, connected, and engaged with the latest developments, achievements, and opportunities within the program. The newsletter includes programmatic updates with key information that may affect or impact their experience with the program. To ensure that the newsletter is accessible (i.e., easy for auto readers, text descriptions for images, font, and colors), visually appealing, and easy to navigate, the program utilized Smore, a popular newsletter platform known for its user-friendly interface and engaging design capabilities.

The newsletter was implemented as an intervention to highlight the program's commitment to transparency, community building, and the overall success of each member of the program. This includes information such as policy updates (i.e., national and state-level legislation) to stay up to date with advocacy efforts and potential impact on family decision making, schedule changes (for students and staff members as it impacts day-to-day functioning of the program), and other essential information that can be shared with the masses (such as celebrating student success in various areas of the program). Recognizing the importance of easy access to information, the newsletter includes hyperlinks as needed directing readers to additional resources, detailed updates, and essential services. These links are strategically placed to provide a seamless experience, allowing families and students to find more in-depth information with just a click.

Implementation

Celebrating success is considered a strong value of the IPSE program discussed in this article. Each newsletter features one or two students, highlighting their achievements, contributions, and stories. This section not only fosters a sense of pride and accomplishment within the students, but also serves as an opportunity to celebrate one another's growth and/or successes amongst their peers. Next the newsletter includes an overview of programmatic updates or student services, encompassing extracurricular opportunities, and planned social events. The program also issues timely reminders about utilizing these services to ensure that the IPSE program students have all the support they need to succeed. The newsletter also includes an update on each of the five core areas of the program: 1) academics, 2) employment, 3) independent living, 4) personal and social skills, and 5) health and wellness, while offering insights into new initiatives, projects, and how students can get involved for each. This intervention aims to help families understand the comprehensive nature of the program and the opportunities available for students as their time in the program progresses.

By leveraging Smore's analytics features, the program can track engagement and reach, including who has viewed the newsletter. Tracking engagement and views in this way allows program staff to continually improve communication, ensuring that messages are effectively reaching the intended audience.

The bi-monthly newsletter plays a key role in informing parents/guardians of programmatic updates by offering timely and relevant information that supports families in their journey. By consistently updating families on policy changes, schedule adjustments, and student achievements, the newsletter ensures that they remain informed and engaged while gradually reducing the need for direct intervention. This method not only prepares students for independence but also maintains a connection with the program, providing a balanced approach to support.

Parent/Guardian Drop-In Meetings

Description of Intervention

The IPSE program discussed in this article hosts six parent/guardian drop-in meetings via Zoom™ each month. These drop-in meetings can range anywhere from a brief 15-minute check-in, to one hour of content provided to update families on specific areas of the program as a whole. Five of these drop-in meetings are aligned with the five domains (academics, employment, independent living, personal and social skills, and health and wellness) within the program and are hosted by the instruction coordinator who oversees that domain. The remaining drop-in meeting is hosted by a graduate assistant who leads sessions including topics that may be of interest to parents and guardians, such as supporting young adults in fostering two-way communications skills, navigating the dating and relationship world as a support for their young adult, and more (Hebert & Patten, 2024). The purpose of these meetings is to provide a specific time for parents and guardians to meet with the instruction coordinator hosting the meeting to discuss new developments or information to be aware of related to that domain within the program. During these drop-ins, parents are encouraged to ask general questions they may have regarding the specific domain area, while being reminded to maintain the privacy of each student by not sharing specifics about their young adult during this time. Because these meetings occur in a group setting, private, confidential, or sensitive information is not discussed. The topics of these drop-ins vary based on the domain and current events in the program. Additionally, parents and guardians have the potential to benefit from being able to relate to one another in the questions they ask or experiences they have while learning about new program developments together in a group setting.

Implementation

Staff within the IPSE program collaborate at the beginning of each semester to set dates for each drop-in meeting. Staff collaborates so that there is not more than one drop-in on the same day and that the drop-ins occur within a reasonable timeframe of each other, allowing parents and guardians to have planned communication with an average of one staff member per week through these meetings. These dates are communicated to parents and guardians in the bi-monthly newsletter discussed previously and through Outlook calendar invites containing Zoom™ meeting links for each drop-in meeting. The host of the meeting takes notes on which parents/guardians attended the meeting and the topics that were discussed, as well as any questions that were asked to ensure follow up takes place after the meetings.

As families prepare for life after the program, it is essential to gradually reduce the level of support provided through these drop-in meetings. This process involves progressively decreasing the frequency of these meetings and varies by topic and encouraging families to seek out resources and build their networks independently. Initially, the number of meetings is reduced to bi-weekly, and eventually, to monthly check-ins. By maintaining some level of consistent communication through the periodic meetings, one can ensure families are still informed and connected while fostering greater independence. This strategy helps families transition smoothly from the program, confident in their ability to support their young adults in the broader community post-program.

Parent Liaison Role and Supports

Description of Intervention

The goal of the parent liaison role for the IPSE program and parents/guardians of program students is to facilitate a positive relationship between the families and program staff. The liaison role supports families as they navigate their changing roles and assists families by offering emotional support and a different perspective. Additionally, the parent liaison provides guidance and serves as a safe, non-biased buffer. The parent liaison role cannot alter or change programmatic policy but does give input into policies and procedures and encourages a parental/family perspective on that input. The liaison works with the director of the IPSE program to keep parent perspectives in all decisions while maintaining a student-focused approach. This role does not serve as a mediator between families and staff, but instead a support to the families to help them as they transition and to decrease the frequency of families reaching out for emotional support from program staff that may be better delivered from another parent.

Implementation

The person(s) serving as liaison signs a confidentiality agreement and non-disclosure agreement and is also a volunteer who is not financially compensated. The position has been filled by a parent of a student who completed the program for the past two years and previously was filled by a parent who helped create the specific IPSE program discussed in this article. Parents/guardians are introduced to the parent liaison each summer, and they connect with the families via telephone, text, and email. Once school is in session, the liaison connects to families by sending a weekly to bi-weekly email to offer support. The support provided includes helping break down policies and procedures, discussing situations that may arise, frequent communication, check-ins, and support. The parent liaison logs interactions and/or questions and concerns and consults with the director as needed.

As students matriculate from the basic to the advanced program and progress through their years in the program, the frequency of support and check-ins from the parent liaison gradually decrease. Initially, families receive weekly communications, which then shifts to bi-weekly and eventually to monthly check-ins from the liaison as they become more familiar with the program, more self-reliant and confident in their young adult's ability as they progress through the program. This phased reduction in support helps families build confidence in their fading of support of their young adult while also supporting their young adult's independence and ensuring they remain informed and connected.

Recognizing that an influx of support requests typically occurs as families prepare to transition out of the program, the parent liaison adjusts the frequency of check-ins to meet these increased needs. During this critical period, the liaison will provide more frequent support to address specific concerns to help facilitate a smooth transition. By carefully managing the fading of support, the IPSE program is able to help families receive the appropriate level of assistance throughout their journey, ultimately preparing students for greater independence beyond the program.

Person-Centered Approaches

Although the IPSE program discussed in this article implements some system-centered approaches as discussed previously, to keep parents/guardians informed of programmatic updates, student- and family-specific interventions are still needed to ensure students and their supports (i.e., parents/guardians) alike feel supported in areas considering their unique needs, experiences, and values throughout the young adult's time in the IPSE program, as well as feel prepared for life outside of and post-program. Beth Mount's text, *Person-Centered Planning: Finding Directions for Change Using Personal Futures Planning* (1997) differentiates person-centered planning from system-centered planning by noting that system-centered planning is usually based upon what one might generalize or stereotype about a group of individuals with shared disabilities; organized to please funders, regulators, policies, and rules; and only offer a limited number of options whereas person-centered planning can help to craft a more desirable lifestyle for the individual, design an unlimited number of options for experiences, focuses on quality of life, and emphasizes the individual's idea of meaningful experiences, dreams, and desires.

These person-centered approaches are also critical to ensuring IPSE programs consider how cultural competencies might impact each family or support team's perspective on goals, values, and meaningful experiences. Hamilton and colleagues (2021) outline four fundamentals of culturally competent practices when working with families from different backgrounds and experiences in their 2021 article, which comes from looking at each student and their family system as their unique unit versus a collective whole within the program itself:

"1) Understand how a family makes meaning of the disability," as cited in Avdi et al. (2000).

"2) Understand how a family describes their child's characteristics," identified by Hamilton et al. (2021).

"3) Understand how a family copes with the disability," as cited by Gray (2003).

"4) Understand how and where a family decides to seek or not seek intervention for the disability," as cited by Hilton et al. (2010).

Authors from the Grigal, Paiewonsky, and Anselm's (2023) Delphi study investigating essential components and activities within inclusive college-based transition services also reported data supporting transition programs developing a stronger emphasis on using more culturally responsive interventions. Recommendations to do so from their study includes presenting information to families or support systems in a way that they, as a unit, can fully understand expectations. To meet the need for person-centered approaches for student success and parent/guardian needs for support while respecting each unit's unique experiences, values, and desires, the program utilizes intervention strategies including weekly student-led emails, Parent Summer

Challenge, and program phone/direct contact meetings, which can be viewed in the later half on the right side of Figure 1.

Weekly Student-Led E-mails

Description of Intervention

Within the IPSE program described in this article, each student enrolled participates in an Organization and Planning course every semester. In this course, students are asked to write a weekly email to their parents/guardians, practicing communication skills while sharing details about their week. Students under self-guardianship can opt out of sharing this email with their parents/guardians, but still complete the activity. A total of 17 of the 24 students enrolled during the 2022-2023 academic year are under self-guardianship. Students use a Google document with prompts to reflect on their past week to help create their email. The prompts align with the five domains of the program, and students provide details regarding the activities they participated in over the past week in each domain. Additionally, there is a prompt for students to write about what activities they were involved in over the weekend. This format allows students to share individualized updates with their parents/guardians.

Implementation

The weekly student-led emails are crafted and disseminated each week classes are in session. Initially, staff members create an outline of topics to discuss in the email for each student and assign them to a separate Google document. With student permission, staff members invite students' parents/guardians to collaborate on the document to see student updates to these prompts about the student's week. Students are prompted to write in complete sentences and give specific details about each domain to practice writing and communication skills while at the same time allowing parents and guardians to read about their young adult's weekly experiences in their own words and to encourage that communication regarding day-to-day life be facilitated between the student and parent/guardian..

As students progress through the IPSE program, the frequency and format of the weekly student-led emails are gradually adjusted to promote greater independence and self-reliance. Initially, some students may require significant guidance and structured prompts to complete their weekly emails. However, over time, the prompts can be simplified, and students are encouraged to take more ownership of their updates.

Parents and guardians often request more detailed and frequent updates as their young adults prepare to transition out of the program. While the program aims to meet these needs, it is also important to balance this with the goal of fostering independence in students. Therefore, as students advance through the program, the frequency of staff-facilitated prompts decreases, encouraging students to independently reflect on and communicate their weekly experiences.

Ultimately, families need to determine what the future of these updates looks like beyond the program. The program staff support this transition by gradually reducing direct involvement in the email process, allowing students to develop their communication skills and enabling families to establish their routines and expectations for updates post-program. This approach ensures that students are prepared for greater independence while still maintaining strong communication with their families.

Parent Summer Challenge

Description of Intervention

The Parent Summer Challenge is an optional intervention for parents/guardians that focuses specifically on IPSE program students and their parents/guardians who are completing their first academic year and transitioning into their second year enrolled in the IPSE program. The need for this intervention was discovered after the staff of the IPSE program recognized that parent/guardian goals and student goals began to shift or change following students' first year enrolled in the IPSE program. As students are exposed to the program's five domains throughout their first year (e.g., academics, independent living skills, health and wellness, employment preparation, and personal and social skills), students and parents/guardians alike might identify new growth in their skill set as well as a shift in priorities of these goals. This growth could change expectations for student outcomes post-program that might have been discussed as part of the student's original goals set at the start of the program. As a result, this intervention aims to create a dialogue between the program director and parents/guardians to ensure student needs and goals are centered in a realistic way as the young adult continues to progress through the program. In the two years this intervention has been implemented an average of 64% of students and parents transitioning into their second year of the program opted to participate and completed all parts of the challenge. This includes five out of six possible parent-student dyads from the summer of 2022 and four out of eight possible parent-student dyads from the summer of 2023. By being highly individualized, the outcomes from this intervention can help the IPSE Director communicate updated individual expectations and hopes of parents/guardians and students as stakeholders of the program to consider as they move into the second year with the IPSE program.

Implementation

The Parent Summer Challenge is implemented over May, June, and July while students return home for summer break. The intervention consists of three parts:

1) *Wellness Wheel Completion:* Parents/guardians and students are each given two copies of an intervention called the Wellness Wheel. The Wellness Wheel is a self-report measurement scale asking the individual completing it to rate on a scale from 1-10 how satisfied they feel in eight areas of wellness: Employment/occupational wellness, social and relational wellness, physical wellness, academic/intellectual wellness, financial wellness, mental/emotional wellness, environmental/independent living wellness, and spiritual/cultural wellness, which was derived from Witner and Sweeney's (1992) model of wellness based on a multi-dimensional approach investigating quality of life for individuals outside of solely a medical approach.

2) *Student Share:* Upon completion of the Wellness Wheels separately, parents/guardians are encouraged to set up a time to discuss the outcomes of the wheel with their young adult/student to identify where perceptions might differ in how the student is achieving wellness in each area. Parents/guardians are encouraged to identify at this stage which areas of wellness are most important to them versus which areas are most important to their young adult through conversing about the results of the Wellness Wheels.

3) *Staff Share:* After discussing with their young adult, parents/guardians are encouraged to set up a time to meet with the IPSE program director and a graduate assistant to discuss outcomes discovered from completing and comparing the Wellness Wheels. During this meeting, the director facilitates discussion between the IPSE Director, parent/guardian, and graduate assistant. In contrast, the graduate assistant acts as a note-taker to document responses to questions to disseminate to the staff later. The dissemination of parent/guardian and student reflections help to inform new/reinforced focuses for the student as they transition into their second year of the program. The goal is to implement these focuses in a way that honors both student perspectives as well as

parent/guardian perspectives as a valuable member of the student's support team.

Program Phone and Direct Contact Meetings

Description of Intervention

Should additional student-specific or family-specific concerns arise that cannot be addressed by the other interventions listed above, parents/guardians can schedule individual direct contact meetings with staff during working hours. Additionally, IPSE program staff members from the program discussed in this article are available to students and parents/guardians through an on-call cell phone for after-hours support. This phone number is shared with all students and their parents/guardians in the event of an emergency or needed support when staff are not in the office. When a student calls this number, the staff member with the phone is available to help them with their emergency need. With many families located over 100 miles away, as depicted in Table 2, program staff are often students' closest resources. This phone allows students to call and have immediate assistance with their needs. The on-call phone also provides a sense of security to parents and guardians by providing reassurance that their young adult will receive assistance quickly and that someone is prepared to establish communication should a need arise (such as a student needing immediate feedback related to decision-making or in the event of an emergency).

Implementation

Parents/guardians can schedule a direct contact meeting during working hours by contacting the program director or individual staff member via phone or email that they wish to schedule a meeting. Prior to a meeting being scheduled, program staff continue to encourage parents and guardians to discuss concerns and questions with their young adult directly as the primary source of information to promote student autonomy and privacy. This effort is an attempt to ensure that the meeting need could not otherwise be addressed by facilitating communication between the parent/guardian and their young adult. To encourage the use of the on-call phone as needed after hours, the program phone number is shared with students and families when they attend program orientation, and it is re-shared each year in the program handbook. During program orientation, students save this number into their phone contacts and label it as "EAGLES Emergency Contact." When a call is received on the phone, program staff will address the need and follow up with needed individuals regarding the incident. Each program staff member is assigned to be responsible for the on-call phone for two to three weeks each school year. All calls are recorded within student records housed by the program so staff can track trends for after-hour calls. If a trend is identified as a common call theme, program staff may re-evaluate how that need can be addressed through a follow-up direct contact meeting.

Discussion

The interventions discussed in this article represent one IPSE program's attempt to include parent/guardian perspectives as valuable members of their young adult's support network during their time in college through both system-centered ways that preserve program resources such as time and funding, as well as person-centered approaches that honor each student and family's unique experiences and needs. While the IPSE staff aim to provide quality support to students during their time in the program, it is also essential to consider what will be available to students post-program that will continue to help them practice skills learned and move towards achieving goals set both before and during program enrollment. The authors hope that by describing these approaches used to establish communication with parents and guardians in one southeastern IPSE program, other IPSE programs might try to implement and evaluate whether these interventions are a good fit considering the resources available to them, as well as parent/guardian needs within their respective programs.

Limitations

With research and practitioner implemented supports, there are a few significant limitations to note while sharing these IPSE program parent/guardian interventions/supports. The authors recognize that not all resources are equal regarding each IPSE program's infrastructure available for funding, time, and staff available to provide support desired by parents/guardians. While these interventions may be realistic for some, they may not be the best fit for all; each program must consider its stakeholder's specific needs and ability to implement support based on available resources. Additionally, these interventions were created using recommendations from current policy and literature available on parent/guardian supports, the authors note that parent/guardian support and involvement is an area within the IPSE field that could continue to be explored to add to gaps in the literature of how to best utilize parents/guardians as valuable resources when it comes to student outcomes. Research on post-program outcomes considering how supports and resources available outside of programs are preparing young adults with intellectual disability to continue to strive towards their life goals post-program involvement.

Future Practice and Research

With many of these interventions discussed in this article being piloted to meet the needs of parents/guardians expressed in program evaluation from 2022, ongoing program evaluation of these interventions will be crucial to determine usefulness in the long-term of providing parent/guardian supports that prioritize student autonomy and success. To better inform continued refining and implementation of parent/guardian supports as it relates to student success, the interventions discussed in this manuscript that have been developed and implemented over the last two years (2022-2024) are planned to be included for review in program evaluation taking place in Spring 2024. This data will help to continue evaluating how parents and guardians value the mixed approach of generalizable and person-centered approaches while supporting their young adults in the IPSE program.

References

Agarwal, R., Heron, L., & Burke, S. L. (2021). Evaluating a postsecondary education program for students with intellectual disabilities: Leveraging the parent perspective. *Journal of Autism and Developmental Disorders*, *51*(7), 2229–2240. https://doi.org.spot.lib.auburn.edu/10.1007/s10803-020-04676-0

Avdi, E., Griffin, C., & Brough, S. (2000). Parents' constructions of the 'problem' during assessment and diagnosis of their child for an autistic spectrum disorder. *Journal of Health Psychology*, *5*(2), 241-254.

Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. § 1232g; 34 CFR Part 99 (1974).

Foley, K. R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation, 34*(20), 1747–1764.

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, *56*(3), 631-642.

Grigal, M., Hart, D., Papay, C., Bukaty, C., Choiseul-Praslin, B., & Pound, S. (2024). *Annual Report of the Cohort 3 TPSID Model Demonstration Projects (Year 3, 2022–2023)*. University of Massachusetts Boston, Institute for Community Inclusion. https://thinkcollege.net/sites/default/files/files/resources/22-23_TPSID%20Annual%20Report_R.pdf

Grigal, M., Hart, D., Smith, F. A., Domin, D., Sulewski, J., & Weir, C. (2014). *Think College National Coordinating Center: Annual report on the transition and postsecondary programs for students with intellectual disabilities (2012-2013).* University of Massachusetts Boston, Institute for Community Inclusion.

Grigal, M., Paiewonsky, M., & Anselm, T. (2023). A Delphi Study to Confirm Essential Components and Activities of Inclusive College-Based Transition Services: Essential Components of College-Based Transition. *Journal of Inclusive Postsecondary Education*, *5*(1). https://doi.org/10.13021/jipe.2023.3280

Hamilton, M. B., Brusnahan, L. L. S., & Pearson, J. N. (2021). Culturally competent educational practices: Supporting students with disabilities and their families. *DADD Online 8,* 114-128. https://exceptionalchildren.org/sites/default/files/2023-04/doj_2021.pdf?_gl=1*gvvhmx*_ga*MzIxNjIxNzkyLjE3MTg3MjUyMTY.*_ga_L4ZFTNESGT*MTcxODcyNTIxNi4xLjEuMTcxODcyNTM3MC42MC4wLjA.

Hebert, C. C., & Patten, B. S. (2024). Caring connection: Strengthening communication between parents/guardians and inclusive postsecondary education program staff. *Journal of Inclusive Postsecondary Education, 6*(1). https://doi.org/10.13021/jipe.2024.3662

Higher Education Opportunity Act. (2008). *U.S. Department of Education.* https://www2.ed.gov/policy/highered/leg/hea08/index.html.

Hilton, C. L., Fitzgerald, R. T., Jackson, K. M., Maxim, R. A., Bosworth, C. C., Shattuck, P. T., Geshwind, D.H., & Constantino, J. N. (2010). Brief report: Under-representation of African Americans in autism genetic research: A rationale for inclusion of subjects representing diverse family structures. *Journal of Autism and Developmental Disorders*, *40*(5), 633-639.

Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Kohler, P. D., Gothberg, J. E., Fowler, C., and Coyle, J. (2016). *Taxonomy for transition programming 2.0: A model for planning, organizing, and evaluating transition education, services, and programs*. Western Michigan University.

Lee, S. (2009). *Overview of the Federal Higher Education Opportunity Act*. Think College. University of Massachusetts Boston, Institute for Community Inclusion.

MAC Stuff. (2021, July 30). *The changing role of families* [Video]. YouTube. https://www.youtube.com/watch?v=GbghajidC74

Madaus, J. W., Kowitt, J. S., & Lalor, A. R. (2012). The Higher Education

Opportunity Act: Impact on Students with Disabilities. *Rehabilitation Research, Policy, And Education*, *26*(1), 33-42.

Meral, B. F., Wehmeyer, M. L., Palmer, S. B., Ruh, A. B., & Yilmaz, E. (2022). Parental habitus in promoting self-determination of children with/without intellectual and developmental disabilities in Türkiye. *Research in Developmental Disabilities, 131*, N.PAG. https://doi.org.spot.lib.auburn.edu/10.1016/j.ridd.2022.104347

Miller, K. D., Schleien, S. J., White, A. L., & Harrington, L. (2018). "Letting go": Parent perspectives on the outcomes of an inclusive postsecondary education experience for students with developmental disabilities. *Journal of Postsecondary Education and Disability*, *31*(3), 267-285

Morningstar, M., Turnbull, A., & Turnbull, H. R. (1995). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children, 62*(3), 249-260.

Mount, B. (1997). *Person-centered planning: Finding directions for change using personal futures planning*. Graphic Futures.

PACER. (2015). Inspiring possibilities: *Prepare your child for age of majority and transfer of rights.* National Parent Center on Transition and Employment. https://www.pacer.org/transition/resource-library/publications/npc-19.pdf

Stinnett, C. V., Lazo, R., & Pound, S. (2023). "*Think higher. Think college." A resource guide for inclusive postsecondary education for students with intellectual disability.* Institute for Community Inclusion University of Massachusetts Boston. https://thinkhighered.net/uploads/TCcampaign-resource-booklet_R-fixed.pdf

Think College National Coordinating Center Accreditation Workgroup. (2021). *Model accreditation standards for higher education programs for students with intellectual disability.* Institute for Community Inclusion University of Massachusetts Boston. https://thinkcollege.net/sites/default/files/files/TCreport_accred_modelstanda rds_2021.pf

Virginia Commonwealth University (2021). *Direct support professionals orientation: The value of dignity of risk*. Virginia Commonwealth University, Partnership for People with Disabilities. https://dsporientation.partnership.vcu.edu/section-i/the-value-of-dignity-of-risk/

Wehman, P., Targett, P., & Young, C. (2007). Off to work for individuals with autism: A supported employment approach. *Autism Advocate, 46*(1), 54-58.

Correspondence concerning this paper should be addressed to Betty S. Patten, College of Education, Department of Special Education, Rehabilitation, and Counseling, Auburn University, Auburn, AL. Email: bjs0017@auburn.edu

Evaluating Ohio's Postsecondary Programs for Students with Intellectual Disability: A Survey of Program Directors

Jessie C. Green, Andrew Buck, and Margo Izzo
The Ohio State University Nisonger Center

Abstract: Ohio's Statewide Consortium (OSC) conducted a survey of program directors, which sought information about each program's current practices or future plans to implement standards and quality indicators detailed by the Think College Standards for Inclusive Higher Education (TCSIHE). The TCSIHE set benchmarks to design and implement high-quality postsecondary programs for students with intellectual disability. The purpose of this paper is to report the results of the OSC program director survey and share implications for enhancing the quality of programs and consortia nationwide. Four of five program directors completed the survey in their entirety. Twenty-three areas of strength were identified as being fully implemented by the four program directors. Ten areas for improvement are identified and discussed at length.

The disability rights movement achieved a monumental victory in 2008 with the reauthorization of the Higher Education Act of 1965, which is now known as the Higher Education Opportunity Act, Public Law 110-315 (HEOA, 2008). The HEOA of 2008 introduced important provisions to increase access to postsecondary education options for students with intellectual disability (SwID), including the authorization of grants to support the development of inclusive higher education programs to specifically serve this student population. After three 5-year funding cycles (i.e., 2010 – 2015, 2015 – 2020, and 2020-2025), the HEOA has funded over 125 programs across 34 states, including 8 of the 10 programs in Ohio, which are collectively known as Ohio's Statewide Consortium (OSC).

The study described in this paper was driven by a desire to evaluate our programs from the perspective of program directors. An assessment of the different programs provides us with valuable information to improve our programs and strengthen our consortium's ability to provide targeted technical assistance and professional development to partner institutions. We aimed to learn what our programs were doing well and where our programs can make improvements, to increase the quality of the services we provide to students. Thus, our study was guided by the following research questions: (1) What are the main areas of strength across OSC programs? (2) What are the main areas for improvement across OSC programs? and (3) How can OSC employ program evaluation results to continuously improve the quality of individual programs and its consortium model?

To evaluate Ohio's postsecondary programs that serve SwID, the OSC conducted a survey of program directors, which sought information about each program's current practices or future plans to implement standards and quality indicators detailed by the Think College Standards for Inclusive Higher Education (Think College, 2020). The purpose of this paper is to report the results of the OSC program director survey and share implications for enhancing the quality of programs and consortia nationwide. A brief overview of the nation's policy effort to build, enhance, and sustain high quality inclusive postsecondary education (IPSE) programs for SwID precedes the study and results to provide context for our approach to program evaluation.

Higher Education Opportunity Act of 2008

The HEOA of 2008 has changed the demographic landscape of colleges, universities, and other postsecondary programs across the US by increasing access to postsecondary education for SwID. The American Association on Intellectual and Developmental Disabilities (AAIDD, 2021) categorizes ID as one type of developmental disability that originates before the age of 22. The HEOA also refers to SwID as students who are currently, or were formerly, eligible for a free appropriate public education (FAPE) under the Individuals with Disabilities Education Act. Section 760 of the act characterizes a SwID as a student with significant limitations in intellectual and cognitive functioning, as well as adaptive behavior, including conceptual, social, and practical adaptive skills (HEOA, 2008). Significant limitations in intellectual functioning and cognitive ability, which may be determined by an IQ test score of 75 or below, influence how an individual learns, reasons, and problem solves (AAIDD, 2021). Conceptual skills potentially impacted include: (i) language and literacy; (ii) money, time, and number concepts; and (iii) self-direction. Social skills include: (i) interpersonal communication; (ii) social responsibility and social problem solving; (iii) self-esteem; (iv) gullibility and naïveté; and (v) the ability to follow rules and obey laws. Practical skills include: (i) activities of daily living, personal care, and healthcare; (ii) occupational skills; (iii) travel and transportation; (vi) following schedules and routines; and (v) use of technology. Significant limitations in intellectual functioning and adaptive behavior have traditionally been insurmountable barriers to accessing higher education for SwID (Lipscomb et al., 2017; Wagner et al., 2005). In the last decade, however, the HEOA of 2008 has been building and enhancing IPSE programs across the nation to specifically support this underserved population of students.

Comprehensive Transition and Postsecondary Programs

Part D of the HEOA (2008) establishes model projects and programs to provide SwID access to quality higher education through comprehensive transition and postsecondary (CTP) programs. CTP programs offer degree, certificate, and non-degree options for SwID who want to continue academic, career-technical, and independent living instruction at an accredited institution of higher education to prepare for gainful employment. These programs include advising and curriculum structures specifically designed to support SwID advance their career goals. Students are required to spend at least half of their time in one or more of the following activities: (1) enrollment in credit- or noncredit-bearing coursework with nondisabled peers; (2) auditing or participating in coursework within inclusive classroom settings; and (3) participation in internships or work-based training with nondisabled individuals (HEOA, 2008). Importantly, inclusion in general education and paid employment have been identified as evidence-based predictors positively correlated with improved post-school outcomes in employment, education, and independent living for secondary students with disabilities (Mazzotti et al., 2021; Test, 2016). Recent studies have found that participation in IPSE programs supports positive employment outcomes for SwID compared to those who did not attend such programs (Moore & Schelling, 2018; Sannicandro et al., 2018).

Transition Programs for Students with Intellectual Disability

HEOA (2008), Part D, subpart 2 authorizes Transition Programs for Students with

Intellectual Disability (TPSID) and funds model demonstration projects through 5-year grants awarded by the United States Department of Education. The awards fund the creation or expansion of high-quality, inclusive model CTP programs for SwID. Individual institutions of higher education (IHE) or consortiums of postsecondary schools are eligible to apply for awards to establish programs that promote the successful transition of SwID into IPSE programs and onto competitive, integrated employment. IHEs or consortia receiving these awards must provide individualized supports and services to SwID through their programs, in order to promote academic and social inclusion within coursework, extracurricular activities, and other components of the institution accessed by nondisabled students. Programs are required to implement person-centered planning to develop a course of study for each SwID that focuses on academic enrichment, socialization, independent living and self-advocacy skill development. Career skill development and integrated work experience is prioritized to support transition from the program to gainful employment. Programs are also required to partner with at least one local education agency to support SwID who are still eligible for special education services under IDEA. Additionally, CTP programs must create and offer a meaningful credential to students who complete the program, and they must make plans to sustain the program after the grant period ends. The essential requirements of TPSID funded projects described above scaffold essential practices, services, and supports that improve transition outcomes for young adults with disabilities, including career awareness, career and technical education, community experiences, goal setting, inclusion in coursework with their nondisabled peers, self-advocacy and self-determination skills, self-care and independent living skills, social skills, student support, transition programming, work experiences, and youth autonomy (Mazzotti et al., 2021; Test, 2016). Moreover, person-centered planning to teach employment skills is an effective practice to improve postsecondary outcomes for transition-aged students with disabilities (Rowe et al., 2021).

Evaluating TPSID Model Projects

To evaluate the TPSID model projects, HEOA (2008) established a national coordinating center (NCC) to collect and analyze data collected from TPSID programs. The NCC collects program and student-level data, evaluates program outcomes, and publishes annual reports (Grigal et al., 2021). Program level data includes program characteristics, academic access, student supports, and integration of the program within the institution of higher education. Student level data includes student demographics, course enrollment, employment activities, and engagement in student life. In 2011, the NCC published the Think College Standards for Inclusive Higher Education (TCSIHE), and the current 2020 revised version details standards, quality indicators, and benchmarks for high quality inclusive higher education programs (Think College, 2020). The standards and associated quality indicators and benchmarks are aligned to HEOA requirements (e.g., alignment with the institution of higher education, coordination and collaboration with internal and external partners, fiscal sustainability, and on-going evaluation) and student outcomes (e.g., academic success, career development, and campus membership). The TCSIHE may be leveraged by program developers and administrators as a checklist to continuously guide, review, and evaluate program practices for quality improvement. For this

Table 1

Overview of OSC Program Sample

School	TPSID Program	Type	Credential	Unpaid Work-Based Learning (2018-19)	Paid Employment or Work Experience (2018-19)	Paid Employment w/in 90-Days of Exit (2018-19)
Columbus State Community College	Comprehensive Model for Postsecondary Education and Transition Enrichment (COMPETE)	2 Year CTP	1. Human Services Assistant Certificate 2. Early Childhood Aid Certificate	92% (*n*=11)	55% (*n*=6)	45% (*n*=5)
Marietta College	Pioneer Pipeline	Secondary	1. Pre-Transition (ages 14-17) 2. Transition (ages 18 - 22) 3. Employment Readiness Certificate (ages 18+)	67% (*n*=8)	8% (*n*=1)	100% (*n*=1)
Ohio State University	Transition Options in Postsecondary Settings (TOPS)	2 or 4 Year CTP	Workforce Development Certificate	76% (*n*=19)	56% (*n*=14)	85% (*n*=6)
University of Cincinnati	Transition and Access Pathway (TAP)	4 Year CTP	Certificate of Completion	37% (*n*=10)	56% (*n*=15)	50% (*n*=14)
Youngstown State University	Transition Options in Postsecondary Settings (TOPS)	4 Year Non-CTP	Certificate of Completion	100% (*n*=5)	80% (*n*=4)	66% (*n*=3)

study, Ohio's Statewide Consortium, a partnership of IPSE programs for students with disabilities offered at select Ohio colleges and universities, utilized the Think College standards tool to create a survey and evaluate its programs through the perspectives of program directors. The next section will describe OSC with a focus on specific institutions that participated in the program director survey.

Ohio's Statewide Consortium (OSC)

In 2010, The Ohio State University used their TPSID grant to create the Transition Options in Postsecondary Settings (TOPS) program for students with intellectual and developmental disabilities. In 2015, a second award to OSU was used to enhance the existing program, expand new programs in Ohio through subawards, and form a collective body of partner institutions that offer inclusive higher education programs across the state, collectively known as Ohio's Statewide Consortium (OSC). As of this writing, OSC is comprised of 10 partner institutions: (1) Bowling Green State University – Firelands; (2) Cleveland State University; (3) Columbus State Community College; (4) Kent State University; (5) Mount Vernon Nazarene University; (6) Sinclair Community College; (7) The Ohio State University; (8) University of Cincinnati; (9) University of Toledo; and (10) Youngstown State University. Table 1 provides a summary of OSC programs that participated in this study. For more information, go to https://ohioconsortium.wixsite.com/osconline.

Method

Survey Development

A survey was determined to be the best method to gather information from program directors regarding alignment to the Think College Standards for Inclusive Higher Education, due to the large number of standards being assessed. The standards were reviewed, and questions were developed by research team leads to address (all or applicable) quality indicators related to program-level data that directors would be able to answer using the rating scale. An iterative process began at this point in which all members of the research team were given the opportunity to review and provide feedback. Once their feedback was taken into consideration, the survey was given to an external evaluator and expert reviewer from Think College for feedback. Upon completion of the iterative review process the final survey was built within Qualtrics.

The final survey had a total of 65 questions. The first five questions were consent and demographic questions. The remaining 60 questions fell across the eight domains of the Think College Standards listed in Table 2. Each of the questions within the eight domains was rated with the following scale:

I. Yes, planning to implement within next year.
II. Yes, initial implementation and piloting currently.
III. Yes, fully implemented; all students involved.
IV. NO, we are NOT implementing this quality indicator and I am not aware of any plans to implement.

This scale was created by the authors as a way for program leaders to measure their own programs, but not impose the authors ways of implementing the standards, as each institution is individualized.

Participants and Data Collection

The program director survey was sent via email to directors of IPSE programs at five OSC institutions. It was decided to only gather data from program directors because

Table 2

Question Count for TCSIHE

Standard	Question Count
Alignment with College Systems and Practices	9
Coordination and Collaboration	8
Sustainability	8
Evaluation	6
Self-Determination	8
Academic Access	7
Career Development & Employment	8
Campus Membership	6
Demographic Questions	5

there was a varying level of knowledge of overall program scope between administrators and staff. The five programs were chosen because they had received TPSID funding through The Ohio State University and had submitted data to the Think College data network at some point during the 2015-2020 grant cycle. The additional five OSC programs either did not exist during the 2015-2020 grant cycle (*n*=2) or they did not apply to the OSC for funding (*n*=3).

An email was first sent early in the week soliciting participants to complete the survey with a follow-up sent at the end of the week as a reminder to complete. This was done a second time in attempt to gain more respondents.

Analysis

Initially, frequency counts were run on each of the 65 survey questions and reviewed. Upon further review, survey questions were sorted into two categories: (1) areas of strength and (2) improvement areas. Areas of strength were identified as all program directors indicating full implementation. Improvement areas were areas in which one or more program directors indicated either not implementing or planning to implement within one year.

Results

The survey was distributed to program directors for completion between December 2020 and January 2021. Five program directors responded to the survey. Of the five surveys, four met the researcher's definition of being complete (i.e., participants responded to at least 75% of the questions). Only demographic information was completed for the fifth survey, and as such, it was coded as missing data.

Results of the demographic data are not shared as with such a small sample there were concerns of identifying leadership if shared. Table 3 is a report out of the benchmarks identified for further discussion with frequency counts by response. The discussion section reports the full standard, the importance of the standard, and ways to implement the standard based on OSC evidence.

Areas of Strength

Thirty-nine benchmarks were identified as areas of strength across the participating OSC programs. Further review of the strength areas was completed to explore why and how they became areas of strength for these institutions.

Twenty-three of 39 areas of strength were identified as being fully implemented by the four program directors. The program directors reported a mix of full implementation or initial implementation and piloting for the remaining 16 strength areas.

Areas for Improvement

Twenty-six benchmarks were identified as areas of improvement and reviewed for patterns, prioritization of issues, or in need of longer-term planning for improvement. Two of these benchmarks were related to housing. Two of the four program directors work in programs at institutions without student housing options (i.e., community college and secondary program), and therefore answered "No" to these questions. Since housing is not applicable for these institutions, these benchmarks were taken out of the areas for improvement results category, leaving 24 benchmark improvement areas. Seven of eight benchmarks within Standard 3 (i.e., Sustainability) were identified as areas for improvement. They were determined not to be the focus of this article, but rather the focus of the Izzo et al. (2021) article. Of the 17 improvement areas, 10 benchmarks were identified for further review and discussion within this publication.

Table 3 represents the breakdown of program director responses for 10 benchmarks identified as improvement areas for participating OSC programs.

Discussion

The Ohio Statewide Consortia wanted to determine if programs were implementing the Think College Standards for Inclusive Higher Education. As such, the purpose of this study was to conduct a survey in which program directors shared their levels of implementation for each standard and share ways Ohio's programs have put these standards into practice. Many of the strategies are anecdotal examples based on our experience, as this article was written to provide practitioners with tangible ways to enhance their programs.

Areas of Strength

Standard 1: Alignment with College Systems and Practices

All programs surveyed have access to campus facilities (1.1A). Students must have access to all facilities on campus to be truly inclusive. Access to facilities has not come without barriers to work through. For instance, one institution's recreation facility operates on a separate system than the registrar office resulting in some SwID having temporary access restrictions when the data converts inaccurately. Some inter-university phone calls to help SwID get it fixed has resulted in a now seamless process which is additionally a strength of Standard 2.

Table 3

Program Director Response Counts

Standard	No	Yes, i (implement within next year)	Yes, ii (currently piloting)	Yes, iii (fully implemented)	Strength or improvement area
1.1A: Campus facility access	0	0	0	4	Strength
1.4B: Diversity plan	1	0	1	2	Improvement
1.5C: Earning credential	1	0	1	2	Improvement
2.1A: Program director	0		0	4	Strength
2.1B: Program staff	0	0	0	4	Strength
2.1C: Staff supervision and training	0	0	0	4	Strength
2.1D: Student employee and volunteer supervision and training	0	0	0	4	Strength
2.2A: Administration communication	0	0	0	4	Strength
2.2C: Governance participation	2	1	0	1	Improvement
2.3B: Program outreach	0	0	0	4	Strength
3.2C: Network participation	0	0	0	4	Strength
4.1A: Evaluation data	1	0	1	2	Improvement
4.1B: Program changes	1	0	1	2	Improvement
4.1C: Dissemination	1	0	2	1	Improvement
4.2B: Graduate data collection	0	0	0	4	Strength
5.1A: Student-directed planning	0	0	0	4	Strength
5.1B: Plan reviews and revisions	0	0	0	4	Strength
5.2A: Academic self-advocacy	0	0	0	4	Strength
5.2B: Employment self-advocacy	0	0	0	4	Strength

5.2C: Social self-advocacy	0	0	0	4	Strength
5.3A: Role of family	1	1	2	0	Improvement
6.1C: Course enrollment	0	0	0	4	Strength
6.2B: Faculty partnerships	0	0	0	4	Strength
6.2D: Peer mentor supervision and training	0	0	0	4	Strength
6.2E: Satisfactory academic progress	0	0	0	4	Strength
6.2F: UDL Training	1	0	0	3	Improvement
7.1B: Course and career alignment	0	0	0	4	Strength
7.1C: Career Services	2	0	0	2	Improvement
7.2A: Employment staffing	0	0	0	4	Strength
8.1A: Student life engagement	0	0	0	4	Strength
8.1B: Student relationship building	0	0	0	4	Strength
8.1C: Student technology use	0	0	0	4	Strength

Standard 2: Coordination and Collaboration

All programs have a staffing structure to operate the program (quality indicator 2.1), including all programs have a person to oversee program operations (2.1A), employ staff to facilitate aspects of the program (2.1B), and ongoing training for staff and student employees and/or volunteers (2.1C and 2.1D). Program staff have regular communication with campus administration (2.2A) and participate in outreach with current and prospective SwID and families (2.3B).

Collaboration within the program and outside of the program with a variety of stakeholders (e.g., campus administration, families) helps programs maintain a high-quality standard. Providing staff, student employees, volunteers, and any other person supporting the operations of the program with the supports and training necessary for success is an on-going endeavor meant to improve SwID outcomes. Training can come in many forms including attending conferences, completing online modules, and studying resources from Think College including print/electronic or many of their group-based peer collaborations (https://thinkcollege.net/resources).

Standard 3: Sustainability

The OSC discusses sustainability in length in Izzo et al. (2021), but one area of success for the OSC is the development of a state network of programs for students with ID (3.2C). This network, the OSC, has created a variety of methods for communication, coordination, and collaboration, including monthly OSC partner calls with all Ohio programs, a quarterly Postsecondary Advisory Committee, and an ongoing evaluation project. The OSC was successful in working to educate state legislators about CTP programs, which prompted an amendment to make Ohio's PELL eligible students to also be eligible for the Ohio College Opportunity Grant if they are attending a CTP program (https://highered.ohio.gov/educators/financial-aid/sgs/ocog).

Standard 4: Evaluation

Data collection is important to be able to make program improvements, as well as show the strengths of the program to a variety of stakeholders. Collecting follow-up data on graduates (4.2B) can be done in ways to increase response rates. Methods include email or phone calls, hosting alumni social events, or meeting alumni during their scheduled work breaks, particularly for those working at the institution in which the program is housed.

Standard 5: Self-Determination

Participating OSC programs employ a student directed process to develop and monitor student goals (quality indicator 5.1) and practice and improve self-determination skills (quality indicator 5.2). All programs have person-centered planning (PCP) activities (5.1A), which are reviewed each term and modified as needed (5.2B). Each program's process is unique; however, PCPs are led by students and used to develop student's academic, employment, social-emotional skills, and self-determination skills.

There are many ways to develop self-determination skills and this should be a highly-individualized process. Cook et al. (2017) recommend that self-determination skills should be embedded in postsecondary programming based upon previous studies from Shogren et al. (2015) and Wehmeyer et al. (2013). As such, SwID should be supported to develop and use self-advocacy in academic, employment, and social settings (5.2A/B/C).

The following are a small example of how the OSC has built student self-advocacy skills: (1) SwID have participated in the Best Buddies Ambassador training (Best Buddies,

2021) and Project STIR (Ohio Self-Determination Association, 2021); (2) Students enroll in inclusive coursework, such as COMM 2110: Principles of Effective Public Speaking (OSU), or COMM 1071: Introduction to Effective Speaking (Cincinnati); (3) At OSU, students have accessed university workshops to increase these skills, including First Year Experience Success Series, wellness coaching, and Ohio Union Activities Board programming.

Standard 6: Academic Access

Student outcomes are predicated on access to inclusive classrooms and college courses with nondisabled peers (Grigal et al., 2021). This means programs should be working to reduce or eliminate the separate, specialized courses only meant for students with ID (6.1C). OSC staff work to help SwID navigate the wide breadth of available activities to suit these needs. These activities could include brown bag lunch series offered on effective communication, resume writing workshops offered by the campus Career Services office, or a healthy eating on a budget class offered by the wellness department.

With an increase in access to inclusive academic spaces, program staff need to work with faculty to ensure course content is accessible (6.2B). Being sure faculty have access to universal design for learning training is the first step, as this will benefit all students in their classroom, not just those with ID. Alternates to assessment could include an oral exam, in which a SwID verbally answers exam questions, using multimedia to demonstrate learning objectives, and producing a portfolio of work rather than taking a comprehensive written exam. Moreover, many SwID need social supports to be successful in the academic classroom, which can be in the form of peer mentors or educational coaches (6.2D). Workman and Green (2019) lay out steps programs can utilize to establish a peer mentor program.

To maintain the integrity of the program, it is imperative for programs to track satisfactory academic progress (SAP) and course completion for all students (6.2E), regardless of financial aid eligibility. Most university systems do not allow for the systematic nature of maintaining SAP, as there are typically multiple areas reflected outside of enrolled course work. Programs can develop program-level transcripts designed to encompass all areas of SAP, laying out a clear path to graduation for SwID, staff, and families alike.

Standard 7: Career Development

Students in all reporting OSC programs have the option of taking college courses in their areas of career interest (7.1B) and have access to job developers and coaches (7.2A). A robust career development strand within the program model is essential for student success during the program and post-graduation. As mentioned above, SwID need access to a wide variety of inclusive courses, not simply a list of “available” courses. The SwID and staff should be working collaboratively to look across the university to identify courses that meet the needs of the student as identified in the person-centered planning process. Programs need to provide professional development to their job training staff through a variety of avenues, such as webinars, conferences, workshops, and on-the-job training.

Standard 8: Campus Membership

Quality indicator 8.1, access to and support for participation in campus social organizations, has proved to be a strength for the OSC, as all reporting institutions have exposed SwID to campus activities, organizations, and programs of their choosing (8.1A), supported their expansion of personal relationships (8.2B), and used technology to support social communication (8.1C).

There are many ways in which programs can support SwID meet these indicators, including making sure SwID attend and access events. For example, student involvement fairs provide opportunities for students to learn about different organizations on campus and connect SwID with peers to attend activities that they desire. Connecting with university departments, such as The Ohio State University's Digital Flagship initiative, ensure SwID have the same technology as their peers. For many years, undergraduate students at OSU, including IPSE students, were issued university owned iPads to use and are able to download any apps they wish to support all aspects of their lives in college.

Areas for Improvement

As it is not feasible for all of the identified areas for improvement to be focused on at once, ten have been identified as being areas for the OSC to address first.

1.4B Students with intellectual and developmental disabilities are represented in the IHE's diversity plan.

While an institution may not have an IPSE program listed specifically in the IHE's diversity plan, disability should be a facet of the diversity plan. It is important to educate on the importance of recognizing disability and celebrating the representation of it among students, staff and faculty. Representation should go beyond the diversity plan and have meaningful action steps. Programs can help to provide support for trainings needed by faculty and staff to support students or sit on university disability committees, such as an employee or business resource group (ERG or BRG). The program might bring in speakers or events on disability inviting the entire campus community to attend. Finally, engaging with the campus Diversity, Equity, and Inclusion Office to collaborate will help programs be recognized within their university.

1.5C Measurable outcomes to earn the credential are clearly stated and shared publicly.

TPSID programs are mandated to have a meaningful credential. The participating programs in this study all have a meaningful credential. Articulating the steps to earn the credential are important to a variety of stakeholders. First, transparency of earning the credential is vital to the integrity of the issuing body. Next, clear guidelines for earning a credential also lead to a higher quality program. Finally, clear outcomes can lead to higher retention and graduation rates.

Sharing publicly the steps to earn a credential is simply one additional way to validate the credibility of the credential offered by a program. Information on earning a credential should be shared on program websites, during program information sessions, and at recruitment events. Additionally, ongoing dissemination during person-centered planning meetings or other student team meetings of program transcripts or degree audits, and the program handbook should occur.

1.5D Credential completion data is tracked and publicly reported.

Supporting SwID who become alumni is a proud undertaking for a program, and as such, it should be celebrated. One way to celebrate credential completion is to publicly report the number of SwID who have earned credentials. This can be done on a program website or blog, in a newsletter, in institution press releases, and shared during recruitment events. Celebrating IPSE day annually (usually in May) is a wonderful time for programs to share completion data. When reporting credential completion, be sure to report the completion of industry recognized credentials by SwID or degree completion by alumni.

2.2C Program staff collaborate with and participate in faculty/staff governance or committees.

Faculty and staff governance and committees within the university system are an excellent way to bring awareness to the IPSE program. Often, membership of these committees and groups consist of faculty and staff from across the university, most of whom do not have regular access or knowledge of the IPSE program. This is a small way to make connections and coordinate collaboration. Committees that may be most relatable to get involved with on campus are business or employee resource groups or career services subcommittees. Often, there are hiring committees, conference planning committees, and other ad-hoc committees program staff could seek out to bring more awareness of the program. While the focus of this benchmark is staff, students could also get involved in committees with student seats, bringing additional attention to the program.

Quality Indicator 4.1: The program conducts program evaluation and disseminates findings.

All three benchmarks for quality indicator 4.1 were identified as areas for improvement within the OSC. We recognize the importance of data collection from a variety of stakeholders can aide in making programmatic changes, support program development with university administrators, and support an increase in donor dollars, student recruitment, and legislative support. Improving the dissemination of program evaluation outcomes will also aid in the IPSE accreditation process. Programs may utilize the TCSIHE as an evaluation tool to assess areas for improvement and share the results with key stakeholders and public.

4.1A Program staff collect evaluation data from faculty, peer mentors, families, and students. Stakeholders have differing opinions and communication preferences, and as such, programs should facilitate different modes of data collection from partners. Data can be both formal and informal but should be collected at regular intervals determined by program staff. More formal data can be collected using online surveys, through focus groups, interviews, or class assignments for SwID and peer mentors. Informal data may come in the form of class discussions or casual conversations with stakeholders.

4.1B Evaluation data is used to identify and implement needed program changes. Not only is it important to collect evaluation data, it is also important to do something with the data. Data has many uses, but most importantly, it can be used to implement program changes for a higher quality program. Not all changes need to be made at once but be sure to share the changes with stakeholders.

4.1C Program staff disseminates data and evaluation findings to administration, families, and other stakeholders. Dissemination of findings to stakeholders can be used in a multitude of ways to strengthen the program. One tool for disseminated findings is in recruitment of SwID. SwID and families want to be sure the program and institution they are attending is worthwhile. Outcome data of graduates can be shared with SwID and families considering a program, as well as with existing and potential funders of the program for student scholarships.

Faculty may be apprehensive to the idea of a SwID in their course. Evaluation data from other faculty members on the success of SwID in inclusive coursework can help to share the benefits of including SwID in general courses.

Evaluation findings can be disseminated in newsletters, on social media, through email, in videos and at recruitment events, such as information sessions. This is not an all-inclusive list, as the stakeholder and needs of data are likely to dictate the method in which a program disseminates the information.

5.3A The program staff provide training and document procedures that describe the role of family members.

Providing training for families helps families navigate a new area of transition. While families are familiar with schooling, postsecondary education is very different than the K-12 system they are coming from. Providing families with these explicit differences will help families support the SwID advocate for themselves.

Documenting the expectations of family members is vital to SwID success, as it allows for all to understand their role and how to best fill it. Without documentation, families might be overly involved or not involved enough or misunderstand other university policies (e.g., FERPA), leading to frustration and lack of a cohesive team working to support the SwID.

Providing training and documentation can be done in many ways and is done best when these messages are delivered in many modes. Print and electronic communication through email, newsletters, blogs, and social media can support a varying level of importance of the communication based on the channels used to share the information. Some programs choose to have a memorandum of understanding (MOU) with families and SwID while others have contracts. Trainings can be provided face-to-face but also using video conferencing platforms. The expansion of video conferencing in the last several years supports families with busy schedules and those not local to the institution their student is attending.

6.2E College faculty are offered training on Universal Design for Learning principles and/or other topics.

Universal Design for Learning (UDL) is a benefit to all students, not just SwID. Universities should be prioritizing UDL as a strategy to increase retention and graduation efforts. Not all faculty may be aware of UDL or offerings at their university. As such, program staff can share resources, webinars or trainings on UDL with faculty. If a university does not offer professional development regarding UDL, program staff can use this opportunity to develop resources and trainings to give back to and serve the university, as this is for the greater good of the student body. Additional topics that could be beneficial for faculty are offerings on learning more about neurodivergence and supporting neurodivergent students, following disability services protocols, facilitating academic accommodations, and communicating in clear language.

7.1C Program staff collaborate with campus Career Services to benefit students.

Utilizing the university's Career Services Office will benefit SwID. There is likely a broad array of connections to the business community within this space. Much like the UDL professional development mentioned above, there is ample opportunity for the employment staff in a program to provide professional development on career service activities to staff who may have not worked with students with disabilities. Empowering the career services staff will ultimately provide SwID a much more inclusive experience. Career services can look very different from university to university. Having SwID participate in campus-wide career service sponsored activities, such as career fairs, brown bag sessions, or interview preparation will aid in improved employment outcomes for SwID.

Recommendations for Practice

At a minimum, individual programs need to evaluate their program against the TCSIHE and the Inclusive Higher Education Council's Program Accreditation Standards to be sure they are able to serve SwID with the highest quality possible. Taking steps to know where a program stands regularly will allow program leadership to set goals, adjust policy, and use evaluation data to implement and improve each of the TCIHES standards and benchmarks. These standards and benchmarks are designed to continually move the needle toward higher-quality programming for SwID. Aligning institutions with the inclusive standards promotes the sustainability of comprehensive and effective programs.

Finally, programs should continue to create resources for the Think College website. Practitioner informed resources and training materials provide concrete, real-world examples that address technical assistance needs and scale-up best practices. Program leadership and staff should connect in the Facebook group for peer-to-peer networking, problem solving, idea sharing, and celebrating. Lastly, programs should connect with autism and other disability support programs that may be on their campus, such as student organizations, faculty committees, and diversity initiatives.

Limitations and Future Research

Several limitations should be addressed in future research. First, the sample size of this study is small, and therefore a larger sample would aid in a more robust response and illustration of examples to meet individual indicators. Future studies should increase the number of program directors in the sample pool. A national survey can aid in learning more about the strengths and technical assistance needs of programs between states. Second, the TCSIHE are not designed as a series of quality indicators for state or regional consortium operations, therefore there is not a benchmark for what a high-quality consortium can look like. Future research should focus on the development of a set of standards meant to develop and implement high-quality consortiums to support postsecondary program development and expansion.

Conclusion

Access to inclusive postsecondary options for SwID is becoming more prevalent with the support of the Higher Education Opportunity Act of 2008. With an increase in the number of programs, it is essential to promote quality indicators and evidence-based practices that support the success of college students with intellectual disability. Inclusive higher education programs further actualize the Americans with Disabilities Act mandate to provide opportunities for full inclusion in all aspects of society. High-caliber, comprehensive transition programs promote equitable access to critical services and empower students with essential knowledge and skills that enhance positive postsecondary outcomes.

References

American Association on Intellectual and Developmental Disabilities. (2021). *Definition of intellectual disability*. https://www.aaidd.org/intellectual-disability/definition

Best Buddies. (2021). *Best Buddies Leadership Development Programs.* https://www.bestbuddies.org/what-we-do/leadership-development/

Cook, A. L., Wilczenski, F. L., & Vanderberg, L. (2017). Inclusive concurrent enrollment: A promising postsecondary transition practice for building self-determination among students with intellectual disability. *Journal of the American Academy of Special Education Professionals*, (winter), 25-44. https://www.naset.org/publications/ja asep-research-based-journal-in-special-education/jaasep-winter-2017

Grigal, M., Hart, D., Papay, C., Wu, X., Lazo, R., Smith, F., & Domin, D. (2021). *Annual report of the cohort 2 TPSID model demonstration projects (Year 5, 2019-2020)*. University of Massachusetts Boston, Institute for Community Inclusion. https://thinkcollege.net/resource/program-evaluation-student-outcomes/annual-report-of-the-cohort-2-tpsid-model-demonstration

Higher Education Opportunity Act of 2008, Pub. L. No. 110-315, 122 Stat. 3078 (2008). https://www.govinfo.gov/content/pkg/PLAW-110publ315/pdf/PLAW-110publ315.pdf

Izzo, M., Green, J.C., Buck, A., Anderson, E., Weinbrandt, D., Going, J., & Porter, K. (2021). Ohio's statewide consortium: Promoting sustainability of transition and postsecondary programs for students with intellectual disabilities. *DADD Online Journal, 8*(1), 129-141. http://www.daddcec.com/uploads/2/5/2/0/2520220/doj_2021.pdf

Lipscomb, S., Hamison, J., Liu Albert, Y., Burghardt, J., Johnson, D. R., & Thurlow, M. (2017). *Preparing for life after high school: The characteristics and experiences of youth in special education. Findings from the National Longitudinal Transition Study 2012. Volume 2: Comparisons across disability groups.* Full Report. NCEE 2017-4018. National Center for Education Evaluation and Regional Assistance. https://ies.ed.gov/ncee/pubs/20174016/index.asp

Mazzotti, V. L., Rowe, D. A., Kwiatek, S, Voggt, A., Wen-Hsuan, C., Folwer, C. H., Poppen, M., Sinclair, J., & Test, D. W. (2021). Secondary transition predictors of postschool success: An update to the research base. *Career Development and Transition for Exceptional Individuals, 44*(1), 47-64. https://doi.org/10.1177/2165143420959793

Moore, E. J. & Schelling, A. (2018). Postsecondary inclusion for individuals with an intellectual disability and its effects on employment. *Journal of Intellectual Disabilities*, *19*(2), 130-148. https://doi.org/10.1177/1744629514564448</p>

Ohio Self-Determination Association. (2021). *Project STIR.* https://osdaohio.org/project-stir/

Rowe, D. A., Mazzotti, V. L., Fowler, C. H., Test, D. W., Mitchell, V. J., Clark, K. A., Holzberg, D., Owens, T. L., Rusher, D., Seaman-Tullis, R. L., Gushanas, C. M., Castle, H., Chang, W., Voggt, A., Kwiatek, S., & Dean, C. (2021). Updating the secondary transition research base: Evidence- and research-based practices in functional skills. *Career Development and Transition for Exceptional Individuals*, *44*(1), 28-46. https://doi.org/10.1177/2165143420958674

Sannicandro, T., Parish, S. L., Fournier, S., Mitra, M., & Paiewonsky, M. (2018). Employment, income, and SSI effects of postsecondary education for people with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, *123*(5), 412–425. https://doi.org/10.1352/1944-7558-123.5.412

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education*, *48*(4), 256-267. https://doi:10.1177/0022466913489733

Test, D. (2016). *Evidence-based practices and predictors in secondary* *transition: What we know and what we still need to know*. National Technical Assistance Center on Transition. https://transitionta.org/

Think College. (2020). *Think college standards for inclusive higher education.* (Rev. ed.). University of Massachusetts Boston, Institute for Community Inclusion. https://thinkcollege.net/sites/default/files/files/tc_standards%2Bchecklists_draftFeb2020_0.pdf

Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). *After high school: A first look at the postschool experiences of youth with disabilities. A report from the National Longitudinal Transition Study-2 (NLTS2)*. SRI International. https://files.eric.ed.gov/fulltext/ED494935.pdf

Wehmeyer, M. L., Palmer, S. B., Shogren, K. A., Williams-Diehm, K., & Soukup, J. H. (2013). Establishing a causal relationship between intervention to promote self-determination and enhanced student self-determination. *The Journal of Special Education*, *46*(4), 195-210. https://doi:10.1177/0022466910392377

Workman, M., & Green, J. (2019). *How to Think College: Establishing a peer mentor program.* Issue No. 5. University of Massachusetts Boston, Institute for Community Inclusion. https://thinkcollege.net/sites/default/files/files/resources/HTTC_05_Establishing_Peer_Mentor_Program_R.pdf

The OSC was initially funded through a model demonstration grant (P407A150080) supported by the Higher Education Opportunity Act (PL 110–315). The views expressed do not reflect those of the US Department of Education. Correspondence concerning this article should be addressed to Jessie Green, The Ohio State University Nisonger Center, 371H McCampbell Hall, 1581 Dodd Dr., Columbus, OH 43210. E-mail: green.1798@osu.edu

“You don’t Know What You Don’t Know”: Intentionally Connecting Individuals with Autism and Law Enforcement Officers to Increase Safety

Melissa A. Sreckovic
University of Michigan-Flint

Christine K. Kenney
Grand Valley State University

Alyssa M. Golden
Ridge Wood Elementary School, Northville Public Schools

Ray Hall
Chief of Police
University of Michigan-Flint

Heather Bromley
Police Lieutenant
University of Michigan-Flint

Abstract: This article reports the outcomes of a study designed to create and execute a community event known as "Officer Friendly Day". The primary goal was to facilitate positive interactions between individuals with autism and their families and law enforcement officers, while also exploring the perspectives of volunteers and community members in attendance. Interviews and surveys were employed to gain insights from law enforcement officers (n = 3), community members (n = 4), and volunteers (n = 6). The findings revealed Officer Friendly Day successfully fostered positive connections between individuals on the spectrum, their families, and law enforcement officers, contributing to increased awareness and understanding of autism. Understanding the perspectives of law enforcement officers, community members, and volunteers is crucial to provide guidance to researchers and community members who design, implement, and refine events similar to Officer Friendly Day, which aim to ultimately enhance the safety of individuals on the spectrum in the communities they live, learn, and grow.

The increasing prevalence of autism spectrum disorder (ASD) has garnered expanded attention in recent years, with the Center for Disease Control reporting a notable rise, estimating that approximately 1 in 36 children in the United States are now diagnosed with ASD (Maenner et al., 2023). This surge in diagnoses necessitates an exploration of the intersection between autism and law enforcement, given the higher likelihood of interactions between individuals with autism and law enforcement officers (LEOs). Studies reveal individuals on the spectrum engage with LEOs at a higher rate than the general population, with reported prevalence ranging from 7.9% to 32.5% (Cooper et al., 2022).

Reasons for interactions necessitating a law enforcement response most often include disruptive behavior, suspected neglect or abuse, non-criminal behavior, and wandering/elopement (Gardner et al., 2022).

Individuals with autism exhibit a higher likelihood of elopement and wandering compared to the general population, potentially resulting in reports of them being missing (Law & Anderson, 2011). Behaviors typical of autism, such as stimming, may be mistakenly perceived as suspicious (Debbaudt, 2002). Encounters between LEOs and individuals on the spectrum can occur in various contexts, including routine traffic stops, in the community, or incidents at home or school, where officers may intervene in response to instances of escalated behavior among individuals on the spectrum (Wallace et al., 2021). Additionally, individuals with autism may find themselves involved in different roles within the criminal justice system, either as victims of a crime (Mayes, 2003; Petersilia, 2001) or as witnesses or suspects (Teagardin et al., 2012; Woodbury-Smith & Dein, 2014). It is important to highlight there is limited evidence supporting the notion that individuals on the spectrum are more prone to intentional criminal acts than their neurotypical peers (Ghaziuddin et al., 1991; Mouridsen, 2012). In fact, data from the United States Bureau of Justice indicates individuals with disabilities, including those with ASD, are nearly twice as likely to fall victim to crimes compared to individuals without disabilities (Harrell, 2017).

The distinct features of autism, including repetitive verbal or physical movements, may lead to misunderstandings during encounters with law enforcement. For instance, stimming may be misinterpreted as suspicious activity, potentially escalating interactions. This misinterpretation is compounded by the sensory challenges faced by many individuals on the spectrum, which can be exacerbated by the presence of LEOs and their vehicles at the scene. Unfortunately, many LEOs do not have adequate training on how to appropriately engage with and support individuals with autism (Gardner et al., 2019). The consequences of this lack of knowledge are profound, with media reports highlighting traumatic incidents, serious injuries, and even fatalities resulting from interactions between LEOs and individuals with autism (e.g., Moore, 2023; Spocchia, 2021). LEOs responding to calls without proper training of support strategies and prior understanding of common behaviors exhibited by individuals with autism have also resulted in negative perceptions of LEOs by the autism community (Crane et al., 2016; Gardner et al., 2022; Salerno & Schuller, 2019). For example, Crane and colleagues (2016) found less than 20% of individuals on the spectrum and their caregivers categorized an interaction with a LEO as satisfactory. Not surprisingly, parents, caregivers, and professionals have expressed fears of police contact for their loved ones with ASD (Wallace et al., 2021).

The frequent encounters between LEOs and individuals on the spectrum (Cooper et al., 2022) coupled with negative outcomes of these interactions (e.g., restraint, arrest, and death; Copenhaver & Tewksbury, 2019) underscore an urgent need to increase the safety of individuals on the spectrum during public safety encounters. To meet this need, research teams have been developing, implementing and examining the efficacy of LEO training on autism with the ultimate goal of ensuring officer and citizen safety during these calls (Sreckovic et al., 2022). While these trainings have proved to be effective at meeting study objectives (primarily increasing officer knowledge of autism), some LEOs report wanting more than just training. For example, in a recent study conducted by Kenney and colleagues (in press), an officer who participated in a LEO training on autism reported they would like to see more programs where LEOs have the chance to meet with individuals with autism in their community before an emergency response is needed. Another officer shared they would like to better understand the family perspective and what families expect when they arrive on scene (Kenney et al., in press).

Given the increasing rate of autism diagnosis (1 in 36; Maenner et al., 2023) along with the likely engagement between LEOs and individuals on the spectrum, more should be done to bring together the law enforcement and autism communities for relationship building outside of safety and crisis situations. The purpose of this study was twofold. The first aim was to design and implement a community event to build relationships between LEOs and individuals on the spectrum and their families. The second aim was to ascertain the perspectives of LEOs, student volunteers, and community members who attended the event. The research team was particularly interested in better understanding participants' personal experiences on the day of the event, benefits of the event, and ways to improve the event.

Method

Study Aim 1 Framework

A case study framework was utilized to focus on the event as a unique case, allowing for a thorough, multi-faceted, and holistic understanding of its design and implementation (Creswell, 2014). When designing the event, the researchers documented every aspect of the event, from planning to execution, capturing a detailed picture of the event's contexts and activities.

Study Aim 1 Procedures

To develop a community event (i.e., Officer Friendly Day) to bring together LEOs and individuals with autism, two researchers with expertise in autism and two members of a university Department of Public Safety (i.e., Chief of Police and Police Lieutenant) collaborated to form the planning team. To design the event, the planning team collaborated on the goals of the event, activities held at the event, safety information to share at the event, and the setting and physical space of the event. The team also collaborated on how to prepare volunteers, LEOs, and community members for the event. The team met monthly for 4 months and communicated via email and phone frequently leading up to the event. All event decisions were made by the team.

Study Aim 2 Framework

Within the case study framework, interviews and surveys were used to better understand LEOs, student volunteers, and community members' perspectives of Officer Friendly Day. Interview and survey questions centered on individual experiences during the event, benefits of the event, and suggestions to improve the event. Semi-structured interviews allowed for flexibility and depth, capturing detailed personal experiences and perceptions.

Study Aim 2 Procedures

Study procedures for study aim 2 were approved by the university's institutional review board. Nine days after Officer Friendly Day an electronic Google Forms survey was sent to community members who attended the event and registered ($n = 17$). Four community members completed the survey. Please see Table 1 for survey questions. Five to 7 months after Officer Friendly Day, email invitations were sent to all eight education student volunteers who volunteered at the event and five LEOs who volunteered at the event, inviting them to participate in an interview. All interviews occurred on Zoom. More than five LEOs participated in Officer Friendly Day, but the planning team only had access to contact information for five of the officers. Six education students and three LEOs participated in the interviews. Interviews lasted approximately 20–60 min and were

Table 1

Survey/Interview Questions

Community Member Survey Questions

•What did you think about the activities? Were there enough for you and your family to do?
•Do you have any suggestions for additional activities for children and/or adults that we could do at Officer Friendly Day in the future?
•Were any of your needs or the needs of your family NOT met during the event? If so, please describe.
•Is there anything you would like to see changed for next year's Officer Friendly Day event?
•Please share your favorite part about the event.
•Please share any other thoughts you have about the event.

Law Enforcement Officer Interview Questions

•Please tell me your experiences interacting with people with autism?
•Please tell me about your experience volunteering at Officer Friendly Day?
•Did you learn anything new about individuals with autism and/or family members at the event? If so, please describe.
•How will this experience impact your work when engaging with individuals with autism and their families?
•How will this experience impact you as a community member?
•What do you see as the greatest benefit to holding inclusive events like Officer Friendly Day?
•Would you like to see anything changed at future Officer Friendly Day Events?
•Is there anything else you'd like to share?

Student Volunteer Interview Questions

•Please tell me your experiences interacting with people with autism.
•Please tell me about your experience volunteering at Officer Friendly Day.
•If any, in what ways did your experience at Officer Friendly Day connect with your coursework?
•How will this experience impact your future work in your profession?
•How will this experience impact you as a community member?
•What do you see as the greatest benefit to holding inclusive events?
•Would you like to see anything changed at future Officer Friendly Day Events?
•Is there anything else you'd like to share?

facilitated by the third author. All interviews were transcribed verbatim.

Thematic coding (Gibbs, 2018) was used to identify themes across the surveys and interviews. A priori descriptive codes were created based on questions asked in the survey. The first and third authors coded the data independently and then came together to debrief. These coders then moved into inductive coding by using constant comparison to create categories (Strauss & Corbin, 1998). If there was a disagreement in the coding, the coders discussed those disagreements to ensure a consensus coding process. To establish the credibility of the themes, the authors used thick, detailed descriptions with several quotes to describe each theme, and the second author, who was not part of the data collection process, served as an additional check to confirm the researchers' inferences were logical and grounded in the findings (Brantlinger et al., 2005).

Participants

Six education students participated in the study. Four students were studying elementary education, one student was studying secondary math education, and one student was a graduate student earning an alternative route education degree. Education student participant ages ranged from 23–37 and included five females and one male. Five students identified as Caucasian and one student identified as middle Eastern/Arab. Three LEOs participated in the study, two chiefs of police and one police lieutenant. Two participants earned master's degrees and one participant earned a bachelor's degree. LEO experience ranged from 22–30 years in the field. Participants' ages ranged 47–62, two participants identified as male and one as female, and all three participants identified as Caucasian. Four community members completed the survey. Demographic information was not collected for the community members.

Results

Study Aim 1: Design and Implement Officer Friendly Day

For a step-by-step guide on how Officer Friendly Day was designed, please refer to the Officer Friendly Day How to Guide in the Appendix.

Goals of the Event

When designing Officer Friendly Day, the planning team had four main goals for the event: (1) to give individuals with autism the opportunity to engage with LEOs and become familiar with their uniforms, vehicles, and role, so that in the event of an emergency they are familiar with the sights of police vehicles and uniforms as well as the overall duties of LEOs; (2) to give individuals on the spectrum and families/caregivers the opportunity to ask LEOs questions they have about safety and autism disclosure; (3) to give LEOs the opportunity to interact with individuals with autism to become more familiar with the characteristics of autism, so that when they are on a call that involves someone on the spectrum, LEOs may be more comfortable recognizing possible signs of autism and engaging with individuals with autism; and (4) to create a safe space and a judgment-free atmosphere for community members on the autism spectrum and their families/caregivers to be able to engage in a fun, family event where each individual is welcomed and valued for who they are.

Officer Friendly Day Activities

A variety of activities were included at Officer Friendly Day. Several LEO vehicles were available for community members to explore. A sidewalk chalk town and race track were created so community members could zoom hot wheels vehicles. Duplo blocks and big foam blocks were set out on large rectangular tables. Bubbles were available, and bubble wands were taped to the sides of tables so community members with varying fine motor abilities could participate. LEOs read stories aloud every half hour. LEOs were available throughout the entire event to answer specific questions from community members. Pizza and cookies were also provided (gluten-free and vegetarian options were available to accommodate dietary restrictions).

Safety Information Shared at Officer Friendly Day

Sharing safety information was an important part of Officer Friendly Day. Community members who attended the event were given bags that included autism identification cards, safety flyers for families/caregivers on wandering/elopement, and a social story on how to stay safe with the police. The bags also included police badge stickers, police-themed coloring pages and crayons, bracelets promoting autism awareness and acceptance, and a fidget object.

Officer Friendly Day Event Logistics

The event was held at a University located in the Midwest, outside on a large grassy area located by a parking lot from 1:00 p.m.–3:00 p.m. All activities were spread out to give community members room to explore. Several LEO vehicles were lined up on the edge of the grass and parking lot. Vehicle doors were open signaling to community members they were welcome to come and explore.

To prepare community members for the event, all registered community members received an email with a link to a video in which event organizers discussed the event and activities that would occur at the event. To prepare student volunteers and LEOs for the event, the event organizers provided a brief definition of autism and common characteristics of individuals with autism, and what to do during the event. Student volunteers were each assigned an activity and instructed to engage with the community members at the activity. LEOs were asked to show community members their vehicle, engage with the community members at the activities, and answer any questions community members may have. For additional information about the event, please see the Officer Friendly Day How to Guide in the Appendix.

Study Aim 2: Ascertain Perspectives of LEOs, Student Volunteers, and Community Members who Attended Officer Friendly Day

LEOs, education student volunteers, and community members' perspectives of Officer Friendly Day are outlined below. Four themes emerged from the data: experiences with individuals with autism, experiences volunteering/attending the event, benefits of the event, and suggested changes. Seeing as the interview questions differed from the community member survey, two themes were present across all three participant groups (i.e., experiences volunteering/attending the event; changes), and two themes were present across LEOs and education student volunteers (i.e., experiences with individuals with autism; benefits).

Experiences with Individuals with Autism

Both LEOs and education student volunteers noted having prior experiences with individuals with autism; however, only education student volunteers shared personal experiences with individuals with autism. One student volunteer shared, "I was a tutor for a boy with autism in high school, and he was in high school as well. And then also my boyfriend's brother has autism, and I'm with them a lot" (S1). Another student shared:

> Before coming to college, in elementary school, I was close friends with a girl who was on the spectrum. I would be a buddy to her, so I would sit with her at lunch, and do gym or art with her. And then, in high school I became part of the peer-to-peer program. And so, I was the buddy for a senior boy, and I would attend gym with him every day, and work one-on-one with him, get him more involved in the class, because that was a goal on his IEP [Individualized Education Plan] (S4).

All LEOs and student volunteers shared having professional or academic experiences with individuals on the spectrum. All three LEOs who participated in the study had previously received autism training. All student volunteers had experience working with individuals with autism in a P-12 or university setting. One officer shared:

> I would come in contact with individuals, in hindsight, who clearly were on the spectrum. That wasn't immediately known to me, based on the training that I had received earlier in my career and my professional journey, but since then, I've received and it's been followed up by Officer Friendly Day. It's clear that I've had routine, nearly routine, encounters with individuals on the spectrum (LEO 3).

Another officer shared they had several contacts with individuals with autism through a service call or as part of an event they attended (LEO 2). Student volunteers shared a variety of professional experiences including substitute teaching (S 2), working in the early childhood development center on campus (S 4), and experiences in field courses (S 6). One student volunteer shared during their University experience, they worked in a "collaborative setting with people with autism" (S 3).

Volunteering/Attending the Event

We asked participants to describe their experience on the day of the event. Overwhelmingly, everyone felt it was a positive experience and enjoyed the event. LEOs shared how much they enjoyed connecting with the individuals with autism and their families. For example, one participant stated:

> When reading books, I sat down with one young man. He was having pizza, or had the opportunity to have pizza, and his mom was there. And, he was the cutest little guy in the world and I could feel that intuitively that he wanted to connect and was struggling to do that, but open to do that. And with the mom's prompting. So, it was just kind of that organic connection. And I would see him again at Touch-a-Truck. And it's just kind of that you know that there's nothing to be fearful of on both sides. But certainly, that genuine respect. And that respect for the parents" (LEO 3).

This was reinforced by another LEO who shared:

> And then the opportunity to read to the kids and their families was pretty neat. But, as far as the families afterwards...just talking with them and hearing their stories, and how much this means to them and their son or daughter, and the impact it could have" (LEO 2).

A third LEO shared:

> What I loved about Officer Friendly Day was the opportunity to connect with others; to connect with individuals that may be on the

> spectrum, to connect with caregivers, parents, guardians, to connect with those that are experts in the field of education and that led that initiative. I just felt that there was so much to learn, and so many opportunities for interactions to connect from multiple points and multiple connections (LEO 1).

Making connections was clearly a powerful experience at the event for all interviewed LEOs.

Student volunteers shared experiencing a sense of a "judgment free" environment. One student shared, "It definitely was inclusive. Every single thing that I could think of was there. Even opening the bubble containers, which was the station I was at, was inclusive. And, I thought it was a really cool event" (S 5). Another student commented on how the experience connected what they learned in the classroom to practice (S 6).

Community members shared their children enjoyed many aspects of the event, including playing with the cars and wandering around (CM 1), storytelling (CM 2), and exploring the vehicles (CM 3). One community member noted their children enjoyed all the activities (CM 3). Another community member shared the activities were great for both their neurotypical daughter and autistic son. One community member shared they enjoyed that their "son got to see the officers portrayed in a good way" (CM 4).

Benefits

The most apparent theme throughout the data were the benefits of Officer Friendly Day. This theme was prevalent among LEOs and student volunteers. Several subthemes emerged from the data, including impact, relationship building, inclusion, learning opportunities, and safety.

Impact. Several LEOs and education student volunteers noted feeling called to action after the event. One student shared how the experience motivated her to do her own research:

> I think working with other future educators is really exciting, and the facilitators are very, very passionate about issues that many children and people with disabilities go through within this country. So, seeing their passion and seeing how much they care about these issues really resonated with me and inspired me to do my own research (S 3).

The event also resulted in education student volunteers reflecting on how to better accommodate students with disabilities in their future classroom (S 2), wanting to create more community events that are inclusive (S 4), wanting to continue their education on inclusive studies (S 1), looking for resources to share with families (S 1), and being a "community member that connects everyone" (S 5). Finally, one student volunteer shared how this experience will make her more mindful in the future when organizing events. She shared:

> Everyone should feel included in the community that they live in. So, I think maybe when I'm organizing [events], one thing that'd be interesting to see in the future is maybe including, not even going out of my way, but just being aware and mindful about the people in the room...Maybe making sure that there is a voice that advocates for people with autism or any other disability, are included in this space as well (S 3).

LEOs shared how much the event personally impacted them. For example, one officer said, "I don't know if it impacted the child more or impacted me more" (LEO 2).

Another officer shared they were excited to see if they can "lift and shift" components of Officer Friendly Day to other campus events, such as Touch-a-Truck (LEO 1). Officers also shared their desire to spread this information to as many officers as possible. For example:

> We have a duty to de-escalate. We have a duty to ensure safety for everyone. And for this population, our community members, they need a little bit more patience from us. And so, that was really just reinforced by Officer Friendly Day. My desire is to expose it to as many officers as possible (LEO 3).

Building Relationships. Building relationships between individuals with autism, their families, and LEOs, as well as building relationships among community members, was a theme present among the student volunteers and LEO interviews. Student volunteers noted Officer Friendly Day showed them they can include families in a lot more (S 5) and events like Officer Friendly Day connect the community and build relationships among people (S 4). LEOs noted the impact of the relationships built at events like Officer Friendly Day. For example, one officer shared:

> As officers we are exposed to a lot of things. Sometimes it's a call for service and sometimes it could be something as simple as someone locking their keys in their car. But, sometimes they are high stress, high pressure situations, and the ability to form those relationships, have those interactions, will make dealing with those situations, whether it's your keys in the car or something more stressful, much easier for that officer (LEO 2).

Another officer shared the most important part of the event was being "patient and understanding and listening" rather than coming to solve the problem (LEO 3). Finally, one officer shared how rare the experience was to come together with families and individuals with autism:

> It is a noble quest to be everyone's police department, to serve everyone in the community, regardless of classification, regardless of their life journey and some of the difficulties they may be facing. And certainly this is a population that for so long has had and just simply not been trained to interact in a purposeful way and in a focused way. We've had training that mentioned autism and being on the spectrum and interacting with individuals. But, I had never been part of, in my entire career, an outreach effort that tries to bring [together] law enforcement with those on the spectrum and their families, because it's also about the families. And again, it's about service. It's about providing service and keeping people safe… (LEO 3).

Inclusion. Several education student volunteers and LEOs shared comments related to the importance of making people feel included and bringing awareness that everyone is different and should be valued for who they are. For example, one officer shared the event brought "awareness to 'we're all so very different" (LEO 1). Creating a space where LEOs had the opportunity to interact with individuals with autism and families gave them a greater sense of "appreciation for individuals that are on the spectrum and their families" (LEO 3). A student volunteer commented on the importance of people feeling included:

> Especially when the kids feel included, and they feel like they belong in the space, and they feel like people want them to be there, and

> they really value their experiences as a person, not even just as a person with disabilities, but just as a person (S 3).

This was echoed by another student volunteer who overheard a family member share "that was the most their kid has ever interacted in an open community setting like that" (S 6). In summary, creating an inclusive space at Officer Friendly Day provided the opportunity for officers to better understand and recognize the challenges individuals with autism and their families may experience and appreciate the families and individuals with autism for who they are, as well as provide a space where all community members were valued and could be themselves.

Learning Opportunities. Officer Friendly Day afforded LEOs and student volunteers many opportunities to naturally learn about individuals on the spectrum, how to interact and communicate with individuals with autism, and how to interact and connect with families. One officer shared:

> You don't know what you don't know. And so, a lot of times officers don't know about people with autism, and they have limited experience with them. Events like this really drive home that, especially with the interactions and the conversations and the smiles and the laughs (LEO 2).

Another officer shared learning more about the sensory stimulation experiences of individuals with autism:

> I think what I learned through first hand exposure was understanding that noise or environment stimulation can affect individuals on varying degrees in varying levels. That is not something that I had recognized or really known up until Officer Friendly Day (LEO 1).

Both LEO and student volunteers shared learning experiences related to families. More specifically:

> I think that it gave me a lot of cool ideas for how to be inclusive. It really showed me that you have to get down to the nitty gritty of what you're inclusive about. Everything has to be inclusive. And I think that by doing events like this, it showed me that you can include the families in a lot more. You can show the families what you're doing, too (S 5).

This was reiterated by another student volunteer who shared:

> I feel like, again with school and then putting it into practice with the volunteer day, is how to talk to the families, and how to be sensitive to the fact that their child does have a disability, but that doesn't mean that their child is any less than any other child. And, they still deserve all the same experiences, especially with school and education (S 6).

An officer shared one takeaway they had was to "listen to the family members" (LEO 3). Student volunteers also shared learning more about how they can support students with autism in their future classroom (S 3) and gaining them more confidence in interacting with students with autism (S 6).

Safety. The theme of safety was only mentioned by LEOs, but it was an important theme, especially since the ultimate goal of the event is to increase the safety of individuals with autism in the communities in which they live, learn, and grow. One LEO summarized this point by stating:

> At the end of the day the mission of any police agency and the Department of Public Safety isn't to have feel-good days. It's life safety. The greatest benefit [to OFD] is an enhanced life safety. If we were to

> pull up tomorrow on that little boy that was eating that pizza, and he was to see a police officer or if I was to see him, and he was on a street corner and in a bad place, he's not gonna see me and run into traffic" (LEO 3).

Communicating with individuals with autism in the field during a safety call can be challenging, especially if the individual on the spectrum is non-verbal or needs longer to process information. One LEO shared how feeling more comfortable with individuals with autism will make the interaction easier:

> Oftentimes, when you're put into a situation you meet people, different types of people, or different challenges that different people may face, it can be awkward at first just because you don't quite know what to say or how to say it. But, this certainly reinforces that I've done this before. So, it's much easier to interact and communicate with the families and the people that are affected by autism (LEO 2).

When interacting in the field with individuals on the spectrum, the LEO must respond differently. One LEO reported how they will respond differently after participating in Officer Friendly Day:

> And so using patience, realizing that if we leverage patience, that transcends on the street. So, as we come in contact with individuals that are on the spectrum on the street, that's a time to take a deep breath, to turn down your radios and listen and connect. We can be very aggressive very quickly, because we're going call to call. But you'll save more time by taking these techniques that we learned, and then the interaction that just reinforced all of that classroom stuff that took place at Officer Friendly Day (LEO 3).

It was evident that participating LEOs felt Officer Friendly Day will have a positive impact on the interactions between individuals with autism and LEOs who participated in Officer Friendly Day.

Changes

The final theme that arose from the data were changes that could be made to improve Officer Friendly Day in the future. Community members suggested having "games with a cop" (CM 1), having a short session for families led by LEOs after the story about "what to do if your child elopes, how to introduce your autistic child to your local LEO community, etc." (CM 1), having a fenced area (CM 1), partnering with other local organizations to pass out free books (CM 2), and having a K9 present (CM 2, CM 3). LEOs also had several suggestions to improve the event, including growing the event in terms of the families and people that participate (LEO 2), expanding the represented agencies (LEO 2), and building a safety village so LEOs could talk about safety features (e.g., stop signs) in a neighborhood (LEO 3). Student volunteers suggested advertising more for the event (S 5), having more sensory options available (S 1), and having the community members select the book the LEOs read aloud.

Discussion

Summary of Findings and Study Implications

The study aims included designing and implementing a community event to build relationships between LEOs and individuals on the spectrum and their families, and to better understand the perspectives of LEOs, student volunteers, and community members who attended the event. Findings from the study were overwhelmingly positive with a major theme being the benefits such an event has for stakeholders who took part. Participants found the event allowed for relationship building, social impact, inclusion, and learning opportunities. Participants pointed out the opportunity to engage allowed for building awareness and perspective shaping. During the event, individuals on the spectrum and LEOs were given the opportunity to spend time together outside a crisis or safety situation. They played games, ate a meal, read stories, and engaged in conversations. They learned examples how one another behaves, communicates, and builds relationships. Such experiences are invaluable for both individuals with autism and LEOs and go a long way in building understanding and the capacity for positive future engagement. A call to action was a main theme for study participants. Student volunteers and LEOs shared that, following the event, they felt driven to continue connecting with the autism community and possibly planning future events of their own. This finding led the researchers to create the Officer Friendly Day How to Guide. The purpose of this guide is to assist others in planning their own community event with tips, strategies, and lessons learned. Replication of Officer Friendly Day, or other events like it, will increase the social impact and continued work toward inclusion and acceptance for all.

One primary goal for the Officer Friendly Day event was to increase safety when individuals on the spectrum and LEOs engage during a public safety call. LEOs appeared grateful for the opportunity to learn more about the autism community through this event. Participants mentioned greater awareness of how they might engage and communicate with someone in the field who may be on the spectrum following the event. In addition, the relationships built at Officer Friendly Day may impact how individuals with autism interact with officers. As one mother said, she appreciated this event because it allowed her son to “see officers portrayed in a friendly way.”

Finally, study participants provided helpful suggestions for how to improve future Officer Friendly Day events. Community members provided suggestions that might make the event more appealing and less stressful (i.e., safety fencing) and areas where families and caregivers might truly benefit (information sessions led by officers on what to do when a child wanders or how to introduce your child with autism to law enforcement agencies). The law enforcement perspective provided beneficial ideas on expanding community resource representation. And the student perspective data focused on further community outreach and possible community participation (e.g., allowing community members to pick the books read by the LEOs). Such feedback is invaluable to making a community event such as Officer Friendly Day truly collaborative, and recommendations were incorporated into the Officer Friendly Day How to Guide and will be implemented in the planning of future events.

The findings of this study can be used to drive future community-involvement events for individuals on the spectrum and LEOs and also have implications for inclusive community practices. As one participant aptly stated, “you don’t know what you don’t know”, and such events provide opportunities for learning and connection. Individuals with autism, and all those with disabilities, are members of our community. They deserve to have equal access to social participation in the capacity they chose and desire. Officer Friendly Day offered a tailored experience meeting the needs of specific stakeholders (in this case, individuals with autism and their families and LEOs). It is possible to provide other thoughtful, collaborative opportunities to bring together community members to learn and grow together. Officer Friendly Day is one example of such an event.

Limitations and Future Directions

A notable limitation for this work is the absence of the voice of individuals with autism during the planning phase of Officer Friendly Day. The disability community, including those with autism, have long been staunch advocates for equity, social justice, and inclusion. The voices of the disability community must be valued and represented throughout research, especially when that research is focused on the disability context. A growing focus on bringing the expertise, ideas, and lived-experiences to the center of autism research allows for the autism perspective to drive research pertaining to autism (Heselton et al., 2021). Future directions for this work will include individuals with autism and family/caretakers throughout the planning and implementation process. In addition, attendance at the event was lower than anticipated, thus leading to a lower sample for community member participants. For future events, adding the voices of individuals with autism in the planning process will likely shed light on ideas for attracting more attendees and better supporting individuals on the spectrum during the event. The hope is that with annual events, individuals will attend again and again, share their experiences, and invite others. Future planning will include further targeted advertisement of the event to attract a larger audience. A further limitation of this study is the way in which the officers were selected to be part of the interview process. Only officers that researchers had contact information for were approached to be part of the interview process, thus limiting the perspectives of the officer experience during the event.

Conclusion

Individuals on the spectrum have the right to live, learn, and grow in their community. Keeping them safe should be a top priority. Recently, law enforcement agencies have offered and/or mandated autism training in an effort to keep individuals with autism safe. But training alone may not be enough. Intentional opportunities need to be created to connect individuals on the spectrum and LEOs before an emergency situation. Officer Friendly Day is one step to fostering relationships between groups of individuals to raise awareness, to build compassion, and to form foundational understanding. Opportunities to learn and make connections were a driving force for this work, and results of this study suggest Officer Friendly Day was successful at connecting individuals with autism and their families with LEOs, raising awareness and understanding, and building compassion.

References

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*(2), 195–207. https://doi. org/ 10.1177/001440290507100205

Cooper, D. S., Uppal, D., Railey, K. S., Blank Wilson, A., Maras, K., Zimmerman, E., Bornman, J., & Shea, L. L. (2022). Policy gaps and opportunities: A systematic review of autism spectrum disorder and criminal justice intersections. *Autism*, *26*(5), 1014–

1031. https://doi.org/10.1177/13623613211070341

Copenhaver, A., & Tewksbury, R. (2019). Interactions between autistic individuals and law enforcement: A mixed methods exploratory study. *American Journal of Criminal Justice, 44,* 309–333. https://doi.org/10.1007/s12103-018-9452-8

Crane, L., Maras, K. L., Hawken, T., Mulcahy, S., & Memon, A. (2016). Experiences of autism spectrum disorder and policing in England and Wales: Surveying police and the autism community. *Journal of Autism and Developmental Disorders, 46*(6), 2028–2041. https://doi.org/10.1007/s10803-016-2729-1

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed method approaches* (4th ed.). SAGE Publications.

Debbaudt, D. (2002). *Autism, advocates, and law enforcement professionals: Recognizing and reducing risk situations for people with autism spectrum disorders*. Jessica Kingsley.

Gardner, L., Campbell, J. M., & Westdal, J. (2019). Brief report: Descriptive analysis of law enforcement officers' experiences with and knowledge of autism. *Journal of Autism and Developmental Disorders, 49*(3), 1278–1283. https://doi.org/10.1007/s10803-018-3794-4

Gardner, L., Cederberg, C., Hangauer, J., & Campbell, J. M. (2022). Law enforcement officers' interactions with autistic individuals: Commonly reported incidents and use of force. *Research in Developmental Disabilities*, *131*, 104371. https://doi.org/10.1016/j.ridd.2022.104371

Ghaziuddin, M., Tsai, L., & Ghaziuddin, N. (1991). Brief report: Violence in Asperger syndrome, a critique. *Journal of Autism and Developmental Disorders, 21*, 349–354. https://doi.org/ 10.1007/BF02207331

Gibbs, G. (2018). *Analyzing qualitative data* (2nd ed.). SAGE Publications. https://dx.doi.org/10.4135/9781526441867

Harrell, E. (2017). *Crime against persons with disabilities, 2009-2015 – statistical tables*. U.S. Department of Justice.

Heselton, G. A., Rempel, G. R., & Nicholas, D. B. (2021). Integrating community participation interpretive phenomenological analysis: Reflections on engaging with the autism community. *International Journal of Qualitative Methods, 20*. https://doi.org/10.1177/16094069211055575

Kenney, K. C., Sreckovic, M. S., Wallace, M., & Debbaudt, D. (in press). Autism training for law enforcement officers: Perceptions from the field. *Journal of Autism and Developmental Disorders*.Law, P., & Anderson, C. (2011). *IAN research report: elopement and wandering*. http://www. iancommunity.org/cs/ian_research_reports/ian_research_report_elopement.

Mayes, T. A. (2003). Persons with autism and criminal justice: Core concepts and leading cases. *Journal of Positive Behavior Interventions*, *5*(2), 92–100. https://doi.org/10.1177/10983007030050020401

Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., Nguyen, R. H. N., ... Shaw, K. A. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. *Morbidity and Mortality Weekly Report. Surveillance Summaries*, *72*(2), 1–14. https://doi.org/10.15585/mmwr.ss7202a1

Moore, K. (2023, November 17). *Excited delirium cited in teen's death in Jefferson Parish outside of laser tag. WWLTV*. https://www.wwltv.com/article/news/investigations/excited-delerium-cited-in-teens-death-in-jefferson-parish-outside-of-laser-tage/289-f9d0148d-14b3-40bd-907f-3d38db76f560

Mouridsen, S. E. (2012). Current status of research on autism spectrum disorders and offending. *Research in Autism Spectrum Disorders, 6*(1), 79–86. https://doi.org/10.1016/j.rasd.2011.09.003

National Autism Association. (n.d.-a). *NAA's be REDy booklet for caregivers*. https://nationalautismassociation.org/store/#!/NAAs-Be-REDy-Booklet-for-Caregivers/p/57859415

National Autism Association. (n.d.-b). *Safety Alert Cards (Pack of 50)*. https://nationalautismassociation.org/store/#!/Safety-Alert-Cards-Pack-of-50/p/13684412/category=2416348

Pathfinders for Autism. (2021). *What to do during a traffic stop*. https://pathfindersforautism.org/wp-content/uploads/2021/03/What-to-do-during-a-traffic-stop.pdf

Pathfinders for Autism. (2022). *How to interact with police*. https://pathfindersforautism.org/wp-content/uploads/2022/08/How-to-Interact-with-Police.pdf

Petersilia, J. R. (2001). Crime victims with developmental disabilities: A review essay. *Criminal Justice and Behavior, 28*(6), 655–694. https://doi.org/10.1177/009385480102800601

Salerno, A. C., & Schuller, R. A. (2019). A mixed-methods study of police experiences of adults with autism spectrum disorder in Canada. *International Journal of Law and Psychiatry, 64*, 18–25. https://doi.org/10.1016/j.ijlp.2019.01.002

Spocchia, G. (2021). *Video shows police tasing severely autistic man who can't speak.* Independent. https://www.independent.co.uk/news/world/americas/crime/police-video-taser-autistic-man-b1942861.html

Sreckovic, M. A., Kenney, C. K., & Wallace, M. (2022). Autism training for law enforcement officers: A scoping review. *Journal of Autism and Developmental Disorders*, *53*(10), 3835–3846. https://doi.org/10.1007/s10803-022-05692-y

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Sage Publications, Inc.

Teagardin, J., Dixon, D. R., Smith, M. N., & Granpeesheh, D. (2012). Randomized trial of law enforcement training on autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*(3), 1113–1118. https://doi.org/10.1016/j.rasd.2012.02.002

Waites, C. (2023). Simulated pullover experience with autistic individual [video]. *YouTube.* https://www.youtube.com/watch?v=bhGzMoBVT2E

Waites, C. (2024a). Simulated traffic stop 2024 [video]. *YouTube.* https://www.youtube.com/watch?v=VWq_6b0COkg

Waites, C. (2024b). Officer Friendly Day 2024 at UM-Flint [video]. *YouTube.* https://www.youtube.com/watch?v=Wpl-aU0JvBw

Wallace, D., Herbert, J., Tyler, D., & McGee-Hassrick, E. (2021). Interactions between individuals on the autism spectrum and the police: The fears of parents, caregivers, and professionals. *Policing: A Journal of Policy and Practice*, *15*(2), 950–964. https://doi-org.libproxy.umflint.edu/10.1093/police/paaa059

Woodbury-Smith, M., & Dein, K. (2014). Autism spectrum disorder (ASD) and unlawful behavior: Where do we go from here? *Journal of Autism and Developmental Disorders*, *44*, 2734–2741. https://doi.org/10.1007/ s10803-014-2216-5

Correspondence concerning this article should be addressed to Melissa A. Sreckovic, University of Michigan-Flint, Department of Education, 303 E. Kearsley Street, 430 French Hall, Flint, MI 48502. E-mail: msreck@umich.edu

Appendix

Officer Friendly Day Event Guide

What is Officer Friendly Day?

Officer Friendly Day is a free, family-friendly event to celebrate autism and build relationships between individuals with autism and their families and LEOs. This event is geared toward individuals with autism and their families. It is an opportunity for individuals on the spectrum (all ages) and their families/caregivers to engage with LEOs, explore their vehicles, and engage in fun activities.

Why Create an Officer Friendly Day?

There are a lot of reasons to create your own Officer Friendly Day. Here are a few:
(1) To give individuals with autism the opportunity to engage with LEOs and become familiar with their uniforms, vehicles, and job, so that in the event of an emergency they are familiar with the sights of police vehicles and uniforms as well as the overall duties of LEOs.
(2) To give individuals with autism and families/caregivers the opportunity to ask LEOs questions they have about safety and autism disclosure.
(3) To give LEOs the opportunity to interact with individuals with autism to become more familiar with the characteristics of autism, so that when they are on a call that involves someone on the spectrum, LEOs may be more comfortable recognizing possible signs of autism and engaging with individuals on the spectrum.
(4) To create a safe space and a judgment-free atmosphere for community members on the autism spectrum and their families/caregivers to be able to engage in a fun family event where each individual is welcomed and valued for who they are.

What Activities are Included in Officer Friendly Day?

A variety of activities can be included in Officer Friendly Day. Here are some suggestions:

- Law enforcement vehicles to explore
- Hot wheels track with vehicles to zoom
- Interactive safety village
- Sidewalk chalk
- Duplo blocks
- Large foam blocks for building
- Bubbles
- Story time with an officer (officers read stories every ½ hour).
    - Here are some suggestions for books:
        - *Officers on Patrol* by Kersten Hamilton
        - *Let's Meet a Police Officer* by Gina Bellisario
        - *Last Stop on Market Street* by Matt de la Peña
        - *Pete the Cat: I Love My White Shoes* by James Dean

- Crafts
- Games with a cop (e.g., playing catch, racing)
- Coloring
- Chat with an officer
- Question and answer session with an officer
- Traffic stop simulation

A few things to keep in mind:

- Individuals with autism have different levels of motor abilities, so think of activities that are inclusive to all. For example, if you have a bubble station, consider taping a couple bubble cylinders to a chair or table so individuals can easily insert their wand. Holding the cylinder and inserting the wand may be too challenging for some individuals. If you have a car station where people can "zoom" vehicles, consider having some small vehicles (e.g., hot wheels) and some larger vehicles (e.g., construction truck) that are easier to grab and move.
- Individuals with autism may put objects in their mouth, so activities with small pieces (e.g., legos) should be excluded or require close supervision.
- Each activity should have a clear location, so it is obvious to the individual what they are expected to do at that station. For example, a large table with blocks on it signals that on that table they build blocks.
- Individuals will have varying interest levels in the different activities provided. Younger children may truly enjoy some activities but not all. They may shy away from activities that are crowded or where there is a lot of noise, or they may be drawn to noisy activities. Older individuals may be equally interested in activities such as bubbles and blocks, or they may prefer activities such as playing catch with an officer or simply asking questions and engaging in a conversation. The goal is to allow individuals to explore the activities that are of interest to them and also allow them to engage with officers to build relationships.
- Individuals with autism who drive may want to practice "getting pulled over" so they know what to do in the event they get pulled over. It might be helpful for individuals on the spectrum to watch a video prior to participating in the simulated traffic stop. The University of Michigan-Flint created a simulated traffic stop video with an autistic driver that can be used for video modeling (https://www.youtube.com/watch?v=bhGzMoBVT2E; Waites, 2023). You can also provide a social story if the individual would rather read a story to better understand what to do in the event they get pulled over.
- Individuals with autism who do not drive may want to practice "getting pulled over" as a passenger or their families may want to practice. The University of Michigan-Flint created a simulated traffic stop video with an autistic passenger that can be used for video modeling (https://www.youtube.com/watch?v=VWq_6b0COkg; Waites, 2024a). You can also provide a social story if the individual would rather read a story to better understand what to do in the event they are in the car during a traffic stop.

What Do Law Enforcement Officers Do During Officer Friendly Day?

At the event, LEOs will show individuals with autism and their families/caregivers their vehicles, answer any questions families/caregivers and individuals on the spectrum have, and get to know the individuals. Officers might ask community members what they enjoy doing for fun, what they are learning in school, what they want to be when they grow up, etc. Officers engage in activities with the individuals with autism, such as blowing bubbles, making sidewalk chalk art, building blocks, playing catch, sitting down and eating a snack with them, etc.

What Do Volunteers Do During Officer Friendly Day?

We suggest having at least one volunteer at each activity station. Volunteers are encouraged to engage the individuals with autism and their families in the activities. For example, they might play blocks with them, ask what they are building, etc. We suggest having a "Welcome Table" where volunteers welcome community members to the event and pass out any information they would like (e.g., bags with safety related information, trinkets to play with). Volunteers may also serve food. It is helpful if all volunteers wear the same shirt so families and individuals on the spectrum can easily identify who they should go to with their questions.

What is Included in Welcome Bags?

Passing out welcome bags is a great opportunity to educate individuals with autism and their families/caregivers about what they can do to support their own or their child/children's safety. You may also consider adding items for the individuals with autism and their siblings to engage with at the event, such as coloring books and fidgets. You may consider including:

- Safety flyers for families/caregivers. The Be REDy Booklet for Caregivers provided by the National Autism Association has a lot of helpful information (https://nationalautismassociation.org/store/#!/NAAs-Be-REDy-Booklet-for-Caregivers/p/57859415; National Autism Association, n.d.-a). During our event, we included the last page of the booklet in our welcome bags.
- ID cards similar to the one created by the National Autism Association (https://nationalautismassociation.org/store/#!/Safety-Alert-Cards-Pack-of-50/p/13684412/category=2416348; National Autism Association, n.d.-b).
- A social story on how to stay safe with the police.
- A guide sheet on how to interact with the police, such as the one provided by Pathfinders for Autism (https://pathfindersforautism.org/wp-content/uploads/2022/08/How-to-Interact-with-Police.pdf; 2022).
- A guide sheet on what to do during a traffic stop, such as the one provided by Pathfinders for Autism (https://pathfindersforautism.org/wp-content/uploads/2021/03/What-to-do-during-a-traffic-stop.pdf; 2021).
- Police-themed coloring pages and crayons
- Police badge stickers
- Fidgets
- Autism acceptance bracelets

Food

Free food is always a nice gesture at a community event. It is important to be mindful of allergies, such as nut and gluten allergies. Be clear what food will be provided and ask guests to keep the event nut free.

Physical Space

When preparing the physical space for the event, it would be ideal if the event space could be fenced in since individuals with autism may wander and/or elope. If a fenced area is not an option, consider putting up cones to create a physical boundary of where the event is taking place.

On the tables and/or at the stations, you may consider including a core communication board. A communication board may help individuals on the spectrum with limited verbal communication and volunteers engage in conversations

.

Preparing Individuals with Autism for the Event

Attending events can be exciting for some people on the spectrum and overwhelming for others. You can help prepare individuals with autism for the event by providing a short video explaining what will happen at the event (e.g., https://www.youtube.com/watch?v=Wpl-aU0JvBw; Waites, 2024b). Or, you can create a social story and share it with community members.

Whether your organization/department decides to create a video or a social story, it is important to share the video and/or social story with the invitation so that individuals with autism can view it prior to attending the event.

Preparing Volunteers for the Event

Prior to the event, brief LEOs and volunteers on autism. Provide a brief overview of autism, different ways individuals on the spectrum may communicate, and ways they can engage with individuals with autism. For example:

- Autism is a neurodevelopmental disorder, meaning that it affects how the brain grows and functions. It can influence a person's ability to learn, communicate, and interact with others.
- No two people with autism are alike. Some people with autism are independent, hold jobs, drive, are married, and have children. Some people with autism require a caregiver for some, most, or all daily living skills.
- Autism impacts a person's ability to speak, communicate, and answer questions. At the event, you may get to interact with people on the spectrum that use sign language or a communication device to communicate (this may be on an Ipad or another electronic device or on a laminated card). You may also interact with people on the spectrum who communicate verbally and who may have an advanced vocabulary. Verbal communication skills are not a reflection of someone's intelligence.
- Autism impacts a person's ability to socialize and understand social cues. At the event, you may say hello to someone on the spectrum and they may not respond back. That is

okay. Sometimes it takes the person longer to process the information. Just smile and be friendly. Some individuals with autism may not look you in the eye or look away from you when you are talking. That does not mean they are not listening. Keep talking and engaging in the conversation, but try to just ask one question at a time and give a lot of wait time (at least 10 to 15 seconds) for the person to answer.

- Autism affects a person's behavior. You may see individuals on the spectrum (young children, adolescents, and adults) engaging in escalated behaviors. Today, you just get to have fun. As long as everyone is safe and a caregiver/family member is nearby, the caregiver/family member will support the individual on the spectrum. If they ask for help from a law enforcement officer, then by all means support the family and the individual.
- Have fun! Children, adolescents, and adults with autism are more like "neurotypicals" than different. Blow bubbles, eat some snacks, engage in conversation, and have a great time.

After the Event

After the event, thank the law enforcement agencies for coming to the event. Having an officer attend the event could cost their department $200–$300. They are making an investment; one that we want them to continue to make. You can show your appreciation by giving them a certificate of appreciation, autism acceptance pins/bracelets, and/or event t-shirts.

Thinking Beyond the Classroom: Innovative Approaches to Amplify Voices of Students with Disabilities and Their Families

Lynn M. Scott
Indiana State University

Annette Romualdo
University of Minnesota Duluth

Juliana Hirn and Christine Parsons
University of Central Florida

Abstract: Caregivers who advocate for their children in an ableist society relentlessly fight for equal opportunities and challenge societal biases to empower their children to navigate a world that often underestimates their abilities and potential. This article describes an inclusive approach to teacher preparation, placing significant emphasis on family involvement during experiential learning. Through the Valuing All Voices Framework, the authors underscore the importance of incorporating diverse perspectives to effectively address the unique needs of students with disabilities (SWD) and their family constellations. The article highlights the transformative impact of empowering SWD and their families to take an active role in the Individualized Education Program (IEP) process. Additionally, the integration of trauma-informed perspectives is emphasized as essential in creating safe and empowering learning environments, promoting open communication, trust-building, and tailored interventions collaboratively developed to promote healing, resilience, and academic success. By extending beyond traditional classroom boundaries broader societal implications of inclusive education is recognized. Readers gain invaluable insights into equity, diversity, and inclusion (EDI) to empower stakeholders to challenge existing power dynamics and amplify the voices of students and families with disabilities, thus driving meaningful change toward a more inclusive educational landscape.

Teacher preparation programs in the 21st century aim to transform classrooms through an emphasis on inclusive, family-centered, and trauma-informed practices for students with disabilities (SWD); in short, teacher candidates are being prepared to *Value All Voices* within the Individualized Education Program (IEP) process. The active involvement of families in the educational process is integral to students' academic, social, and behavioral growth (Finn, 2020). Data overwhelmingly demonstrates SWD achieve higher rates of success and greater independence when they are, both, included in the general education classroom and their caregivers are empowered to actively engage in the educational process (Castro et al., 2015; IDEA, 2004; Jeynes, 2005).

However, caregivers face innumerable hurdles to accessing a complex and multifaceted special education system. While special education is designed to provide support and accommodations for SWD, navigating the complicated framework and labyrinth of professionals within the education system (and its supports) can be overwhelming and challenging for students and their families (Gershwin et al., 2023; Sanderson & Bumble, 2023; Sanderson & Goldman, 2023). While families are not expected to know the numerous compliance-related policies and procedures within the special education process, understanding the technical jargon and terminology included in their child’s IEP can be a demanding ask (Blackwell & Rossetti, 2014).

To help mitigate these obstacles, preparing teachers to operate from family-centered and trauma-informed perspectives is crucial to creating safe learning environments and promoting healing and resilience for SWD. A family-integrated approach to serving SWD places the student’s family unit at the center, engaging both student and family as integral and active participants in the daily educational progress (Mas et al., 2019; Van der Kolk, 2015). Recognizing families are at the center of a child's development and education, the approach seeks to build strong partnerships between families and educators to support the child's learning and well-being (Bailey & Simeonsson, 1988; Mueller & Vick, 2019). Interventions such as promoting cultural competence among educators and caregivers and considering caregiver perspectives in the IEP process aim to enhance collaboration and support for SWD. As such, teacher education programs must include experiential learning opportunities and reflective practices to prepare future educators for effectively working with families and SWD.

Inclusive education recognizes the importance of actively involving and engaging SWD and their families in the educational process. The number of students ages 3-21 who receive special education services increased from 13% in the 2009-2010 school year to 15% in the 2020-2021 school year, encompassing approximately 7.2 million students currently served under the Individuals with Disabilities Education Act (IDEA, 2004; National Center for Education Statistics, 2022). Ideally, education professionals team with caregivers to support SWD within the classroom, and by extension - within their homes and communities. Yet, caregivers are often solely responsible for meeting a variety of needs for their child with a disability including physical support, emotional support, and social aspects (Finn, 2020), once the child leaves the classroom door. Physically, caregivers often assist with daily tasks such as personal care, mobility, and medication management. Caregivers also play a crucial role in offering a consistent and supportive presence to effectively address the emotional needs frequently associated with disabilities. Socially, caregivers act as a critical link between the individual with disabilities and the outside world. According to the National Council on Disability (NCD, 2020), caregivers also play a critical role in advocating for their child’s needs, communicating with school personnel, and ensuring their child receives appropriate support and resources. Caregivers who advocate for their children in an ableist society relentlessly fight for equal opportunities and challenge societal biases to empower their children to navigate a world that often underestimates their abilities and potential. They advocate for their rights and inclusion in various social and educational settings. Thus, the role of caregivers is crucial to include in developing an IEP.

However, research indicates the voices of important stakeholders often go unheard and are marginalized. To ensure that perspectives meet the specific needs of SWD, it is essential to include the voices of such stakeholders as parents, educators, mental health professionals, and the students themselves (Van der Kolk, 2015). The authors consider family and educator involvement through an experiential, intersectional, and reflective approach acknowledging how disability can result in trauma, oppression, and bias; which ultimately can affect interactions between families, educators, and students. Due to factors such as neglect and social exclusion high risk for trauma is seen in SWD, making it crucial to incorporate trauma-informed perspectives when creating safe learning environments (National Child Traumatic Stress Network [NCTSN], 2017). A trauma-informed approach promotes a sense of empowerment, leading to tailored interventions that meet needs, promote safety and trust, while ensuring cultural responsiveness. In turn, this can help promote healing, resilience, and academic success for SWD (Griffin et al., 2019; Kersten & Van der Zanden, 2020). Additionally, ignoring stakeholders who have experienced trauma can lead to negative outcomes for students and a lack of trust between families and school officials. Research shows actively seeking and incorporating the perspectives of all stakeholders, including students, families, and community members, is crucial for promoting effective trauma-informed care within the school system (Meister, 2006).

Caregiver Roles in Empowering Children with Disabilities

The IDEA legislation mandates the provision of opportunities for caregivers from the outset of the special education eligibility process, encompassing consenting to services and participation on the IEP team (IDEA, 2004; Lammert et al., 2018). Caregiver engagement correlates with enhanced academic achievement (Castro et al., 2015; Jeynes, 2005), increased retention and graduation rates, and improved social-emotional adjustment (Barger et al., 2019). Consistent research underscores caregiver involvement as an essential element for the successful creation of a child’s special education plan (Finn, 2020). Caregivers value collaborative communication with school personnel and the establishment of clear, measurable goals for their child (Bailey & Simeonsson, 1988; Mueller & Vick, 2019). As such, educators must collaborate effectively with families to offer transparent and easily understandable information about the special education system (Gershwin et al., 2023; Kleinert et al., 2020; Sanderson & Bumble, 2023). However, despite these necessities and the benefits of caregiver involvement, obstacles remain, hindering adequate family participation (Weist et al., 2017).

Regrettably, caregivers of individuals with disabilities often confront a daunting journey while navigating the public school system. Their journey is fraught with various challenges, encompassing deficient communication from the school team, inadequate support structures, stigma, discrimination, emotional and physical strain, and constrained resources and time (Gershwin et al., 2023; Kleinert et al., 2020; Sanderson & Bumble, 2023). Caregivers encounter obstacles such as a lack of comprehension of the special education system, struggles in communicating with school personnel, being trauma-informed, and limited access to resources and support, all of which impact the emotional well-being of the student and family (Nickerson & Miller, 2014; Vetter & Radin, 2013). A spectrum of challenges exists in the advocacy process, such as inadequate knowledge about their child's disability, navigating the special education system, and receiving minimal training and support from school personnel (Nickerson & Miller, 2014; Vetter & Radin, 2013). The emotional and financial toll of caring for a child with a disability can exacerbate caregivers' stress as they seek to balance their child's needs with their own obligations and well-being. School personnel can mitigate caregiver stress through improved communication and support for families navigating the IEP process. Such measures as implementing a student-led and family-centered IEP process empower and engage SWD and their families, resulting in more favorable long-term outcomes for all involved (Eisenman et al., 2015; Martin et al., 2006; Shogren & Plotner, 2012).

Key Challenges

Student-led and family-centered evidence-based practice in the IEP process is rarely manifested within our education systems, leading to inadequate understandings of needs and family perspectives. Rather, families are routinely marginalized, judged, and pushed to the sidelines as school personnel dominate the IEP process and meetings, leading to family disengagement and decreased academic outcomes for SWD. As asserted by Koch (2020), preservice preparation programs must incorporate a collaborative approach that transcends mere focus on student learning outcomes, classroom management, and academic content. The imperative to enhance the readiness of preservice teachers to engage with families of students with disabilities was firmly established prior to the reauthorization of IDEA 2004 (Bentley-Williams et al., 2017; Fender & Fiedler, 1990; Nyatuka, 2017; Reed & Monda-Amaya, 1995). Nonetheless, preservice teachers may not sufficiently consider the difficulties confronted by caregivers as they navigate the special education system and advocate for their child. Consequently, teacher training programs often limit aspiring teachers to acquiring knowledge about child development, pedagogy, philosophy, and methodology. Yet, given teachers' role as primary contacts for families seeking special education services (Wilson, 2015), they must also be familiar with the collaborative process.

Justification

Collaboration is mandated in legislation, assessment, IEP participation, placement, transition, behavior support plans, and mediation (IDEA, 2004). Therefore, a teacher's ability to collaborate effectively depends on their ability to listen, which includes listening for feelings, restating content, reflecting on feelings, accepting the speaker's comments, and allowing the speaker to confirm or correct their perception (Bos et al., 2007). Brownell and colleagues (2005) used a framework for effective teacher education programs to compare and analyze teacher preparation practices in general and special education. Features of both programs included an emphasis on collaboration between educators and families in the field. However, the descriptions did not include a focus on improving collaboration with families in the learning opportunity and thematic analysis used, further proving the need to provide knowledge to educators across a continuum of experience levels. Consideration to rectify existing deficits in practice with actionable and collaborative strategies are as such: Offer ongoing workshops to in-service educators focused on effective family engagement strategies, including communication skills, cultural competence, and trust-building. When applicable, encourage educators to undertake action research projects exploring and documenting effective family engagement practices. Utilize technology tools like class websites, online portals, and social media to enhance communication with families.

Within the context of experiential learning and reflective practice, it is imperative to foster collaborative communication and partnerships to enhance the educational experience. Establishing opportunities that promote meaningful interactions and reciprocal engagement among educators, students, and caregivers involves incorporating trauma-informed perspectives into initiatives focused on promoting equity, diversity, and inclusion within educational settings. Recognizing and dealing with the effects of trauma enables us to foster more supportive and inclusive environments. Furthermore, advocating for a comprehensive approach underscores the significance of nurturing engagement, encouraging transparent communication, and establishing trust among all stakeholders engaged in the educational process. A comprehensive approach emphasizes the significance of communal team development for educators, students, and caregivers alike. Lastly, amplifying caregiver perspectives within the IEP process and classroom settings fosters collaboration while ensuring the distinct needs and viewpoints of caregivers are respected and integrated into decision-making procedures.

Beyond Traditional Classroom Boundaries

Experiential learning is a hands-on approach to learning in which students gain knowledge and skills through direct experience (Lee, 2019). Knowledge derived from experience does not end after the activity (Kolb, 2014). To address the void in research to practice concerning family collaboration, consideration should be given to practical application within teacher preparation. Institutes of higher education should develop coursework emphasizing family dynamics, cultural backgrounds, and socioeconomic factors through case studies, role-playing, and interactive discussions. Simulation implementation should include engagement in mock IEP meetings and parent-teacher conferences to build confidence and competence. Projects requiring preservice teachers to design and implement family engagement plans involving interviews with families and creation of supportive resource references provide multifaceted benefits. Establishment of mentorship programming provides an opportunity for practical insights and real-world applications of theoretical knowledge. Service-learning integration offers an opportunity to work with community organizations while compounding family support, deepening situational understanding, and strengthening communication skills. Furthermore, research has shown experiential learning provides preservice teachers the opportunity to develop into effective teachers who can plan, teach, reflect, and commit to their practice (Lee, 2019). The experiential learning approaches discussed previously afford preservice teacher candidates a purposeful activity in which they may commit experiential learning into direct practical application.

Immersive Learning Environments

Direct experience benefits preservice teachers by allowing them to explore teaching concepts and strategies in a low-stakes environment. Experiential learning offers them insight into community stakeholders and how teaching can support students' growth (Yardley et al., 2012). Engaging preservice teachers in experiential learning enriches their pedagogical knowledge and skills. They learn to create positive learning environments, engage students meaningfully, communicate with caregivers and colleagues, and manage classrooms effectively (Afalla et al., 2019). This approach provides hands-on problem-solving experiences (Afalla et al., 2019). Involvement with caregivers prepares preservice teachers for communication regarding students with disabilities (Boveda & Aronson, 2019). Experiential learning also allows them to observe and interact with experienced teachers, learn from mistakes, and develop teaching styles. Teacher educators can prepare novice teachers for their careers through experiential learning initiatives (Lee et al., 2019).

Foundations of Preservice Teacher Learning

The research by Bentley-Williams et al. (2017) emphasizes the potential impact of linking teacher education with practical experiences, highlighting the positive effects on preservice teachers' comfort levels, ability to address dilemmas, and development of coping skills (p. 272). In one such experience, candidates were required to informally interview a parent or caregiver of an individual with a disability across the lifespan and report back as assigned within their course work. Further detailed, within the classroom assignment included an interview of one parent, caregiver, and/or supported decision-maker of an individual with a disability. Interview criteria included: (a) disability, (b) level of family participation in the IEP process and related advocacy, (c) resources provided by school personnel to engage in the IEP process and (if applicable) subsequent transition to adulthood (d) extent of the student-led IEP process in their student's experience, and (e) how to engage family constellations throughout the academic span. The experience discussed presently focuses on enhancing the learning journey of both general and special education preservice teacher candidates enrolled in an introductory exceptional education course (Scott et al., 2023).

Framework for Embracing Diverse Caregiver Perspectives

The National Council on Disability (2018) reports the ongoing segregation of students with disabilities, including pull-out, school-based, and medical-based services, limits their access to the general education curriculum and interactions with typical peers. Utilizing the Valuing All Voices Framework, traditionally applied within healthcare settings, to guide evidence-based inclusionary practice in education can be highly valuable. The Valuing All Voices Framework, initially crafted to enhance patient engagement with a focus on social justice and health equity (Roche et al., 2020), incorporates essential elements such as trust, self-awareness, understanding, acceptance, and relationship-building. Recent revisions to the framework, informed by feedback from individuals encountering barriers to healthcare access due to social inequities, have integrated "education and communication" as core components (Roche et al., 2020). The framework's emphasis on addressing power imbalances to promote inclusion and equity is crucial for tackling exclusionary practices against students with disabilities and their caregivers in public school systems (Roche et al., 2020). Standardizing inclusionary guidelines for healthcare-based and school-based service providers who offer wraparound supports can enhance the inclusive nature of these supports, effectively countering harmful exclusionary practices while simultaneously increasing their efficacy (National Council on Disability, 2018). Embracing the principle of 'Nothing About Us Without Us,' Valuing All Voices ensures the voices of traditionally underrepresented groups are meaningfully included in decision-making processes throughout the entire school-age span (Charlton, 1998; Pandya-Wood, Barron, & Elliott, 2017).

Within the framework, self-awareness, characterized by ongoing introspection and reflection, empowers individuals to discern their needs, motivations, and biases, facilitating informed decision-making and effective communication. Elevated self-awareness enables individuals to identify and rectify biases and blind spots, fostering empathy and understanding of other's perspectives and needs, especially crucial for individuals with hidden disabilities. Fostering self-awareness within educational settings is paramount to ensuring equitable treatment and support.

Trust, a complex construct encompassing psychological, social, and behavioral dimensions, underpins interpersonal relationships and institutional dynamics, including those within public schools. Recommendations from Roche et al. (2020) advocate for open communication, follow-up, and a strengths-based approach to nurture trust, vital for fostering a supportive environment within public school settings.

Comprehension and Empathy

The importance of understanding and acceptance when working with caregivers of children with disabilities cannot be underemphasized. Caregivers often experience high levels of stress, isolation, and may have feelings of inadequacy. Caregivers may feel overwhelmed by the demands of caring for their child and the challenges they face in accessing appropriate resources. Understanding caregivers' unique needs and experiences, as well as acceptance without judgment or discrimination, is crucial for developing a trusting relationship and creating a safe, supportive environment.

Interpersonal Connections

Building relationships with caregivers of children with disabilities is a critical aspect of effective care provision. Caregivers might not be the expert on a specific diagnosis; however, they are unparalleled in understanding their child's needs. Professional cultivation to open lines of communication while attentively addressing concerns to foster collaborative partnerships and trust is imperative. Strong relationships between professionals and caregivers can lead to improved outcomes for children with disabilities and reduce caregiver stress. Building relationships with children who have disabilities is just as important. Doing so can help foster a sense of belonging and inclusion, which can result in improved self-esteem and confidence. Discovery from participants in the study conducted by Roche et al. (2020) included creating warm and welcoming environments, maintaining communication and connections, and allowing the time needed to build relationships.

Promoting Education and Dialogue

Effective education and communication are crucial for professionals engaging with caregivers of children with disabilities. An enhancement proposed for the Valuing All Voices Framework (Roche et al., 2020) ensures participants' comprehensive understanding of health research involvement. Recommendations encompass diverse communication modes, clear process outlines, and validation of comprehension. These components should similarly extend to educational settings, equipping caregivers with preparation for processes, understanding of operations, and clarity on school expectations and services.

Interventions for Healing, Resilience, and Academic Success

The entrenched presence of ableism within educational systems presents a considerable challenge in teacher education, especially concerning efforts to instruct teachers in advocating for their students (Suity & Beneks, 2020). Ableism must be tackled in both higher education preservice programs and teacher professional development. Within special education, there's an inadvertent tendency to label, segregate, and remediate students to fit a perceived "normal" standard, thereby reinforcing the idea of disability as an aspect of "otherness" (Timberlake, 2020). To address ableism, it is imperative to redefine education and grasp the dynamics of disability within educational and familial contexts. By differentiating disability from special education, this approach acknowledges impairments while advocating for inclusive responses that embrace the entire spectrum of human diversity. This stance challenges the notion that certain students are less capable of fully engaging in educational opportunities. Teaching strategies for effective collaboration with other educators, specialists, and caregivers can help to ensure SWD are fully supported. Implementing these measures enables schools to foster a culture of trauma-informed care that respects and integrates the viewpoints of all stakeholders who have encountered trauma.

Ultimately results favor outcomes for students and deeper collaborations with the community enhancing cultural competence. Enhancing cultural competence entails providing training and resources to educators alongside caregivers. Educators should actively learn about students' cultures and backgrounds, integrating this knowledge into their teaching. Caregivers need resources and support to navigate the education system and advocate for their child. Recognizing the importance of caregiver input, educators must empower caregivers to advocate for their child's education. Collaboratively, caregivers and educators can facilitate students in reaching their full potential.

Societal Implications

Training educators and mental health professionals in trauma-informed practices for SWD is paramount to supporting their healing and recovery, while also addressing societal implications. Such training heightens awareness and understanding of trauma's impact on SWD (NCTSN, 2017). A family-integrated approach to serving SWD prioritizes the family unit; echoing psychologist Carl Rogers' humanistic approach (Feigenbaum, 2024); which calls for unconditional positive regard and unbiased engagement with family dynamics (Sarpe & Ladea, 2011). Recognizing families as pivotal to a child's development and education, this strategy aims to cultivate strong partnerships between families and educators, enhancing the child's well-being and learning. Trauma-informed perspectives must delve into the root causes of trauma and adopt a critical reflexive approach to acknowledge its intersectional nature (Barnes et al., 2018). By challenging systems perpetuating trauma while advocating for social justice and equity for SWD, this approach fosters a more inclusive and supportive learning environment (Hansel et al., 2015). Incorporating trauma-informed perspectives, amplifying stakeholder voices, and providing comprehensive training for educators and mental health professionals are essential steps in this process and takes a critical reflexive approach.

Meaningful Change

Upon program completion, teacher candidates are expected to understand how SWD learn and develop, while providing individualized learning opportunities to support their students' intellectual, social, and personal development. With this in mind, a greater goal of teacher preparation programs is to ensure candidates are ready to both ascertain and meet the individualized needs of their students, and also be willing and readied to ensure all students (including SWD) are provided access and equity within the general education classroom. A family-integrated approach to serving SWD places the student's family unit at the center, engaging both student and family as integral and active participants in the daily educational progress. Recognizing families are at the core of a child's development and education, the approach endeavors to cultivate robust partnerships between families and educators to bolster the child's learning and well-being. Teacher education programs must offer preservice teacher candidates the opportunity to consider a caregiver's viewpoint when educating an individual with a disability. The source of learning discussed in this article is based on the premise that caregivers of individuals with disabilities deserve understanding. As well, a community of supportive advocates for individuals with disabilities is aggrandized.

Incorporating opportunities for preservice teachers to participate in real-world experiences with families of students with disabilities is crucial for fostering effective communication and collaboration. By engaging in interviews, future teachers gain firsthand insights into the unique challenges, strengths, and needs of students from their primary advocates and support systems—their families.

Current educators can improve their communication skills by employing similar strategies in their current profession. For example, educators can create an individualized communication plan that includes positive and productive communication strategies (Mann, et al, 2024). This plan can systemize how and when to communicate with caregivers, what information to share, and include preferred communication channels. Educators and caregivers are provided with consistent and transparent interactions to support addressing the unique needs and preferences of each family. The educators also have the opportunity to reflect on the communication plan and revisit if the plan supports their students' success, or can improvements be made. This exercise helps educators appreciate the critical role of family communication in education, emphasizing the importance of building strong, empathetic relationships with families. Educators should be considerate and understanding to the sensitive nature of the topic. In reflection, all should be cognizant of information learned during caregiver interactions, note any personal epiphanies revealed, and consider how they might use information learned in their future practice.

Educators and policymakers can enhance the public school system by comprehending the obstacles caregivers encounter when advocating to address needs, thereby better supporting caregivers and their children. In response teacher-education programs should infuse inclusive narratives to encourage intersectional exploration, offering firsthand accounts and nurturing empathy and comprehension of diverse lived experiences. Providing experiential learning opportunities and professional development allows future and current educators the opportunity to apply their learning in real-life settings, as well as reflect on their future service experience in a classroom setting (Afalla et al., 2019), in addition to providing an opportunity for the educator and caregiver to develop partnerships. Reflection is a powerful part of the learning process, as it allows educators to evaluate their experiences and learn from mistakes (Gao, 2015). Providing aspects of reflection allows educators to become more aware of their own beliefs and attitudes, and to recognize the impact of their experiences on their practice. Through reflection, educators gain insight into their teaching and learning process and can adjust their teaching and learning approaches (Gao, 2015). Providing meaningful opportunities to facilitate intentional collaboration is imperative. Paving the road toward improved opportunities and a future that *Values All Voices* in the special education process necessitates embedding collaborative and reflective learning, which fosters critical analysis of attitudes, beliefs, and actions concerning disability and inclusivity; ultimately prompting a call to action.

References

Afalla, B., Gabatino, B., & Corpuz, D. (2019). Experiential learning courses: The outlooks of pre-service and in-service teachers. *SSRN Electronic Journal*, 3, 32-45. https://doi. org/ 10.2139/ssrn.3738852

Bailey, D. B., & Simeonsson, R. J. (1988). Assessing the needs of families with handicapped infants. *Journal of Special Education, 22*(1), 117-127. https://doi.org/ 10.1177/002246698802200113

Barger, M., Kim, E., Kuncel, N., & Pomerantz, E. (2019). The relation between parents' involvement in children's schooling and children's adjustment: A meta-analysis. *Psychological Bulletin, 145*(9), 855–890. https://doi.org/10.1037/bul0000201

Barnes, C., Mercer, G., & Shakespeare, T. (2018). *Exploring disability: A sociological introduction*. John Wiley & Sons.

Bentley-Williams, R., Grima-Farrell, C., Long, J., & Laws, C. (2017). Collaborative partnership: Developing pre-service teachers as inclusive practitioners to support students with disabilities. *International Journal of Disability, Development and Education*, *64*(3), 270-282. https://doi.org/10.1080/1034912X.2016.1199851

Blackwell, W. H., & Rossetti, Z. S. (2014). *The development of individualized education programs: Where have we been and where should we go now? Sage Open*, *4*(2), https://doi.org/10.1177/215824401453041

Bos, C., Schumm, J. S., & Vaughn, S. (2007). *Teaching students who are exceptional, diverse, and at risk in the general education classroom.* Pearson Education.

Boveda, M., & Aronson, B. A. (2019). Special education preservice teachers, intersectional diversity, and the privileging of emerging professional identities. *Remedial and Special Education, 40*(4), 248–260. https://doi.org/10.1177/0741932519838621

Brownell, M. T., Ross, D. D., Colón, E. P., & McCallum, C. L. (2005). Critical features of special education teacher preparation: A comparison with general teacher education. *The Journal of Special Education*, *38*(4), 242-252. https://doi.org/10.1177/00224669050380040601

Castro, M., Expósito-Casas, E., López-Martín, E., Lizasoain, L., Navarro-Asencio, E., & Gaviria, J. L. (2015). Parental involvement on student academic achievement: A meta-analysis. *Educational Research Review*, *14*, 33-46. https://doi.org/10.1016/j.edurev.2015.01.002

Charlton, J. I. (1998). *Nothing About Us Without Us: Disability Oppression and Empowerment*. University of California Press.

Eisenman, L. T., Pell, M. M., Poudel, B. B., & Pleet-Odle, A. M. (2015). "I think I'm reaching my potential": Students' self-determination experiences in an inclusive high school. *Career Development and Transition for Exceptional Individuals*, 38(2), 101–112. https://doi-org.libpdb.d.umn.edu:2443/10.1177/2165143414537349

Feigenbaum, K. D. (2024). A critique of Abraham Maslow and Carl Rogers as educators. *Journal of Humanistic Psychology, 64*(1), 44-63. https://doi.org/10.1177/00221678231154819

Fender, M. J., & Fiedler, C. (1990). Preservice preparation of regular educators: A national survey of curricular content in introductory exceptional children and youth courses. *Teacher Education and Special Education*, *13*(3-4), 203-209. https://doi.org/10.1177/088840649001300313

Finn, L. L. (2020). Improving interactions between parents, teachers, and staff and individuals with developmental disabilities: A review of caregiver training methods and results. *International Journal of*

Developmental Disabilities, 66(5), 390-402. https://doi.org/10.1080/20473869.2020.1830460

Gao, X. (2015). Promoting experiential learning in pre-service teacher education. *Journal of Education for Teaching, 41*(4), 435–438. https://doi.org/10.1080/02607476.2015.1080424

Gershwin, T., McKittrick, L., & Kilpatrick, A. (2023). The importance of following legal requirements: Factors that lead to parent satisfaction with the individualized education program meeting process. *Journal of Educational and Psychological Consultation*, *33*(4), 369-392. https://doi.org/10.1080/10474412.2022.2145290

Griffin, M. M., Fisher, M. H., Lane, L. A., & Morin, L. (2019). Responses to bullying among individuals with intellectual and developmental disabilities: Support needs and self-determination. *Journal of Applied Research in Intellectual Disabilities*, *32*(6), 1514-1522. https://doi.org/10.1111/jar.12646

Hansel, T. C., Osofsky, J. D. & Osofsky, H. J. (2015). Louisiana State University Health Sciences Center Katrina Inspired Disaster Screenings (KIDS): Psychometric testing of the national child traumatic stress network hurricane assessment and referral tool. *Child Youth Care Forum 44,* 567–582. https://doi.org/10.1007/s10566-015-9313-2

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Jeynes, W. (2005). A meta-analysis of the relation of parental involvement to urban elementary school student academic achievement. *Urban Education*, *40*(3), 237–269. https://doi.org/10.1177/0042085905274540

Kersten, P., & Van der Zanden, R. (2020). Providing trauma-informed care to students with disabilities from diverse cultural backgrounds. In R. van der Zanden & P. Kersten (Eds.), *Trauma-informed care in the classroom* (pp. 103-117).

Kleinert, H. L., Kearns, J., & Shogren, K. A. (2020). *Family engagement in special education services for students with intellectual disability: A scoping review*. National Council on Disability.

Koch, K. A. (2020). "The voice of the parent cannot be undervalued": Pre-service teachers' observations after listening to the experiences of parents of students with disabilities. *Societies*, *10*(3), 50. https://doi.org/10.3390/soc10030050

Kolb, D. A. (2014). *Experiential learning: Experience as the source of learning and development*. FT Press.

Lammert, J., Moore, H., & Bitterman, A. (2018, August*). IDC Parent Involvement Toolkit—Making the most of parent involvement data: Improving quality and enhancing understanding*. IDEA Data Center (IDC). Retrieved from https://www.ideadata.org/resources/resource/1926/making-the-most-of-parent-involvement-data-improving-quality-and-enhancing

Lee, J. F. (2019). Enhancing preservice teachers' professional competence through experiential learning. *Journal of Education for Teaching*, *45*(3), 353–357. https://doi.org/10.1080/09589236.2019.1599507

Mann, G., Gilmore, L., Robertson, A., Kennedy-Wood, L., & Maia-Pike, L. (2024). Little things mean a lot: parent perspectives on positive teacher-parent communication when students have disability. *Teachers and Teaching, Theory and Practice*, *30*(1), 102–115. https://doi.org/10.1080/13540602.2023.2241020

Martin, J. E., Van Dycke, J. L., Christensen, W. R., Greene, B. A., Gardner, J. E., & Lovett D. L. (2006). Increasing student participation in IEP meetings: Establishing the self-directed IEP as an evidenced-based practice. *Exceptional Children*, *72*(3), 299–316. https://doi-org.libpdb.d.umn.edu:2443/10.1177/001440290607200303

Mas, J. M., Dunst, C. J., Balcells-Balcells, A., Garcia-Ventura, S., Giné, C., & Cañadas, M. (2019). Family-centered practices and the parental well-being of young children with disabilities and developmental delay. *Research in Developmental Disabilities, 94*, 103495–103495. https://doi.org/10.1016/j.ridd.2019.103495

Meister, G. (2006). *Theories of change for community interventions in education*. In K. Fulbright-Anderson & P. Auspos (Eds.), *Community change: Theories, practice, and evidence* (pp.323-386). Aspen Institute. https://www.aspeninstitute.org/wp-content/uploads/files/content/docs/rcc/COMMUNITYCHANGE-FINAL.PDF

Mueller, T. G. & Vick, A. M. (2019) An investigation of facilitated individualized education program meeting practice: Promising procedures that foster family-professional collaboration. *Teacher Education and Special Education, 42*(1), 67-81. https://doi.org/10.1177/0888406417739677

National Center for Education Statistics. (2022). *Students with disabilities. Condition of Education*. U.S. Department of Education, Institute of Education Sciences. https://nces.ed.gov/programs/coe/indicator/cgg

National Child Traumatic Stress Network, Schools Committee. (2017). *Creating, supporting, and sustaining trauma-informed schools: A system framework.* National Center for Child Traumatic Stress.

National Council on Disability. (2020). 2020 Progress report on national disability policy: Increasing disability employment. https://www.govinfo.gov/content/pkg/GOVPUB-Y3_D63_3-PURL-gpo143439/pdf/GOVPUB-Y3_D63_3-PURL-gpo143439.pdf

National Council on Disability. (2018). *The segregation of students with disabilities*. National Council on Disability. https://files.eric.ed.gov/fulltext/ED604960.pdf

Nickerson, A. B. & Miller, K. T., (2014). Parent perspectives on the individualized education plan (IEP) meeting: An exploratory study. *Journal of Special Education Leadership, 27*(1), 36-45.

Nyatuka, B. O. (2017). A survey of school-family-community partnerships in Kenya. *Journal of Professional Capital and Community*, *2*(4), 229-243.

Pandya-Wood, R., Barron, D. S., & Elliott, J. (2017). A framework for public involvement at the design stage of NHS health and social care research: Time to develop ethically conscious standards. *Research Involvement and Engagement, 3*(6). https://doi.org/10.1186/s40900-017-0068-1

Reed, F., & Monda-Amaya, L. E. (1995). Preparing preservice general educators for inclusion: A survey of teacher preparation programs in Illinois. *Teacher Education and Special Education*, *18*(4), 262-274.

https://doi.org/10.1177/088840649501800406

Roche, P., Shimmin, C., Hickes, S., Khan, M., Sherzoi, O., Wicklund, E., & Sibley, K. M. (2020). Valuing all voices: Refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach. *Research Involvement and Engagement*, *6*(1), 1-13. https://doi.org/10.1186/s40900-020-00217-2

Sanderson, K. A., & Bumble, J. L. (2023). Parent perspectives: Understanding the postschool concerns of parents of transition-age youth with disabilities. *Career Development and Transition for Exceptional Individuals*, *46*(3), 120-132. https://doi.org/10.1177/21651434221128490

Sanderson, K. A., & Goldman, S. E. (2023). Factors associated with parent IEP satisfaction. *Remedial and Special Education, 44*(3), 184-196. https://doi-org.libpdb.d.umn.edu:2443/10.1177/07419325221111571

Sarpe, M. C., & Ladea, M. (2011). Can the lack of unconditional positive regard change the correct diagnose and the decision of treatment? A case report. *European Psychiatry, 26*(S2), 1326–1326. https://doi.org/10.1016/S0924-9338(11)73031-0

Scott, L. M., Anderson, K., Parsons, C., Hirn, J., Kerns, C., & Romualdo, A. (2023). All the voices: An experiential, intersectional, and reflective approach. In M. Musyoka & G. Shen (Eds.), *Advocating and empowering diverse families of students with disabilities through meaningful engagement* (pp. 223-249). IGI Global. https://doi.org/10.4018/978-1-6684-8651-1.ch012

Shogren K. A., & Plotner A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities*, *50*(1), 16–30. https://doi-org.libpdb.d.umn.edu:2443/10.1352/1934-9556-50.1.16

Suity, M. B., & Beneke, M. R., (2020). Authoring mapping the role of ableism in teacher candidate identity construction. *Critical Education, 11*(15). https://doi.org/10.14288/ce.v11i15.186515

Timberlake, M. (2020). Recognizing ableism in educational initiatives: Reading between the lines. *Research in Educational Policy and Management*, *2*(1), 84-100. https://doi.org/10.46303/repam.02.01.5

Van der Kolk, B. A. (2015). *The body keeps the score: Brain, mind, and body in the healing of trauma*. Penguin Books.

Vetter, D. M., & Radin, E. S. (2013). The struggle for advocacy: Parental involvement in the education of children with disabilities. *Journal of Disability Policy Studies, 23*(2), 81-90.

Weist, M. D., Garbacz, A., Lane K., & Kincaid D. (2017). Enhancing progress for meaningful family engagement in all aspects of positive behavioral interventions and supports and multi-tiered systems of support. In M. Weist, A. Garbacz, K. Lane, D. Kincaid (Eds.), *Aligning and integrating family engagement in Positive Behavioral*

Wilson N. M. (2015). Question-asking and advocacy by African American parents at Individualized Education Program meetings: A social and cultural capital perspective. *Multiple*

Voices for Ethnically Diverse Exceptional Learners, *15*(2), 36-49. https://doi.org/10.5555/2158-396X.15.2.36

Yardley, S., Teunissen, P. W., and Dornan, T. (2012) Experiential learning: Transforming theory into practice, *Medical Teacher, 34*(2), 161-164. https://doi.org/10.3109/0142159X.2012.643264

Correspondence concerning this article should be addressed to Lynn M. Scott, Indiana State University, Bayh College of Education, Department of Teaching & Learning, University Hall 323D, 401 North 7th Street, Terre Haute, IN 47807. E-mail: Lynn.Scott@indstate.edu

Shifting Perspectives on Disability: Family Reflections on a Life Fully Lived with Down Syndrome

Tammy Bachrach,
Azusa Pacific University

Mina Chun
California Lutheran University

Abstract: This study examines the perspectives of adult siblings following the death of their brother, Joseph, a man with Down syndrome, born in 1961. This study explores how family members' lives were impacted by their relationship with Joseph. It evaluates the significant transformations experienced by Joseph's family over the past decades to determine to what extent the discourse of disability remained central to the life history account and how the concepts of disability were deconstructed or changed over time and when reflecting on the person's life history. The findings of the study are organized into the birth story and diagnosis (early 1960s), childhood and education (1970s), adult life (1980-1990s), aging (2020s) and family's reminiscence on life after the death of Joseph. The family narrative demonstrates how their understanding of disability shifted over time, both responding to and differing from the historical academic research and/or socio-political changes enacted during the 1960s and forward. This case study provides a multigenerational perspective and counter-narrative to the medical view of disability that often defines people by a condition, views disability in terms of tragedy and burden, and their families as "at-risk."

Joseph
the most grounded, confident, and happy person
one of the most important people in my life
enriched all of our lives
a model for me
a great role model
a central figure in my life
helped to ground me
helped make me who I am
helped me see the value of family, and
caring for people
not just doing things for yourself
taught us all to love more

The above *found* poem was created using words and phrases (Galvin & Prendergast, 2016; Prendergast, 2009) expressed by Joseph's siblings as they reflected on the 60 years they shared with their youngest sibling, Joseph. Joseph was born and diagnosed with Down syndrome in the early 1960s. These words and phrases contrast highly with the deficit model of disability and the view commonly held by societies worldwide of a "hypothetical tragic life" of a man born with Down syndrome and the imagined suffering of the family (Burke, 2021). Despite research that demonstrates that most individuals with Down syndrome report a good quality of life (Skotko et al., 2011), the majority of infants identified as having Down syndrome via pre-natal testing are aborted based on perceived quality of life issues for the child and family (Burke, 2021).The rate of termination in the US is between 67-85% (Chaiken et al., 2023) and some countries such as Iceland terminate nearly 100% of prenatal infants diagnosed with Down syndrome (Burke, 2021).

Joseph's family reminiscences following Joseph's death motivated this research project. This study explores how family members' lives were impacted by their relationship with Joseph and the significant transformations experienced by Joseph's family over the past decades. Additionally, the study sought to determine to what extent the discourse of disability remained central to the life history account and if and how the concepts of disability were deconstructed or changed over time and when reflecting on the person's life history. Joseph's story is not simply his own but intricately woven with the evolving social and cultural landscape surrounding disability. Born at a time when institutionalization for individuals with developmental disabilities, including Down syndrome, was widely accepted (National Association for Down Syndrome [NADS], n.d.-b), Joseph's life reflects the dramatic societal attitudes and practices that have occurred over the ensuing decades. Even the terminology used to describe his diagnosis has changed, transitioning from the outdated "Mongolism" to the currently recognized "Down syndrome" in the early 1970s (NADS, n.d.-b). This shift underscores the ongoing evolution of societal understandings and their terminological reflections.

The late 1960s and 1970s witnessed growing concern about the inhumane treatment and overcrowded conditions prevalent in institutions for individuals with disabilities (Wehmeyer et al., 2017). This dissatisfaction fueled the emergence of grassroots advocacy groups, culminating in the establishment of the first organization for individuals with Down syndrome in the United States in 1960 (NADS, n.d.-b). These developments highlight the growing voice of advocates and their pursuit of positive change.

Furthermore, the average life expectancy for individuals with Down syndrome has also dramatically increased, rising from an estimated 10 years in the 1960s (CDC, 2020) to a current expectancy of 60–70 years (NADS, n.d.-a). This significant improvement in lifespan has contributed to a growing population of individuals with Down syndrome born in the 1960s who are now reaching their later years. Joseph, who passed away in 2021 at the age of 60 due to Alzheimer's disease, a condition with a higher prevalence among individuals with Down syndrome (National Institute on Aging, 2020), exemplifies this demographic shift.

Early research on the outcomes of nondisabled siblings of children with intellectual disability predicted dire outcomes, which included anxiety, lower sociability, and more behavioral problems (Adams, 1967; Farber, 1963; Gath, 1973). Most current research in this area has continued to evaluate the effects and adjustment of children or adolescent siblings (O'Neill & Murray, 2016). Even though individuals with developmental disabilities are living longer lives, the research on adult siblings of individuals with developmental disabilities is relatively limited. When considering the increased life span of individuals with disabilities, limited research has primarily focused on issues regarding providing care (Cuskelly, 2016). This research assumed that the siblings would take on greater responsibility of caring for their disabled sibling later in life as both disabled and non-disabled family members age (Hodapp & Urbano, 2007; O'Neill & Murray, 2016). O'Neil and Murray (2016) sought to determine if adult siblings of individuals with Down syndrome were at greater risk for anxiety and depression as a result of the increased caregiving responsibility and concluded that adult siblings of individuals with disabilities were more vulnerable to anxiety and depression. However, they noted that this was not evidenced in siblings of individuals with Down syndrome. Researchers have also posited that research on sibling outcomes and perceptions differ based on the type of disability, and therefore, research should be disability-specific (Seltzer et al., 2005). Several current studies have found that siblings of individuals with Down syndrome experience close relationships (Cuskelly, 2016; Hodapp & Urbano, 2007) and that the majority of siblings intend to provide direct or indirect support to their sibling with Down syndrome (Cuskelly, 2016).

Additionally, research has explored the experiences of families with individuals with disabilities (Gabel & Kotel, 2018; Kittay, 2008; Landsman, 1998), focusing on pivotal moments like birth or diagnosis and investigating the perspectives of siblings and families (Hayden et al., 2019; Redquest et al., 2020), however, a gap remains in understanding family members' reflections after the passing of their loved ones with developmental disabilities. Existing research on aging adults with disabilities primarily focuses on end-of-life decision-making, caregiving approaches, and autonomy (Bekkema et al., 2014; Trip et al., 2019; Wagemans et al., 2013). To address this gap, this study focuses on gaining a richer multifaceted understanding of the impact of disability on families by examining the stories, memories, and reflections following Joseph's death and how their understanding of disability evolved through their shared life experiences.

This study utilizes a disability studies framework which allows for a critical analysis of the social, cultural, and political dimensions of disability by interrogating historical practices like medicalization, incorporating insider perspectives, and understanding how social and cultural perspectives have shaped the perception of disability (Davis, 1995; Ferguson & Nusbaum, 2012; Ferri & Connor, 2006; Linton, 1998; Oliver, 1996).

Method

The passing of an individual often initiates a period of profound reflection on the life lived and its influence on those still living. This single-case study utilizes narrative inquiry to explore thick rich retrospective stories of Joseph's family members following his death in 2021. This study is not just a retelling of the family narrative; however, it seeks to actively engage in the interpretation and construction of meaning from those experiences, offering valuable insights into their unique perspectives and understanding of the world (Bogdan & Biklen, 2003; Taylor & Bogdan, 1998). The central focus lies in examining how Joseph and his family's reciprocal and shared life influenced the family's collective understanding of disability.

Joseph's family was unable to organize a traditional memorial service since his death occurred during the global pandemic. Instead, his five siblings collectively wrote a eulogy in remembrance of Joseph, reflecting on his life, his personality, and how he impacted their lives. Joseph's eulogy served as the inspiration for this research study. In addition to the eulogy, this study incorporated various family documents to access the family's perspectives during the relevant periods. These documents included an essay written by Joseph's elder sister in 1980, which offered contemporaneous insights into the family dynamic and perspectives. Reflective writings composed by Joseph's deceased parents, Nancy, a preschool teacher, and Matt, a school counselor, also provided valuable insights during Joseph's childhood. These family documents provided a unique insight into the family's perspectives during the 1980s. They allowed the voices of Joseph's parents to be present in the research, even though they were deceased at the time of the study. Incorporating these family documents added depth and richness to the study's findings, providing a more comprehensive understanding of Joseph's life and its impact on his family. This approach also offered a unique window into the family's historical perspective, which was a valuable contribution to the research.

Alongside the family documents, semi-structured interviews were conducted with eight family members, including five siblings, two nephews, and a niece. Due to the global pandemic and the geographical distance between family members, the semi-structured interviews were conducted virtually. The participant pool comprised two older sisters and three older brothers, aged 59-66, and two nephews and one niece, ages 30-40. The participants self-identified as White and middle-class. The family describes themselves as unique, unafraid to “go against the grain,” and socially minded.

Semi-structured interviews explored participants' reflections on Joseph's life, including major events and transitions, the nature of their relationships, significant memories, and their shared family history. Each interview lasted between 50 and 90 minutes and was recorded and transcribed verbatim to ensure accuracy in the data analysis process.

The study utilized a thematic analysis framework (Braun & Clarke, 2006) to analyze interview transcripts and family documents. First, we took time to become familiar with the gathered data and generate initial descriptive and in-vivo codes. Then, we searched for themes, which were created by categorizing codes that had commonalities across participants and codes. Lastly, we finalized themes by reviewing and comparing themes across all gathered data to define and name the themes.

This study promoted trustworthiness and rigor through member checking and triangulation (Creswell & Guetterman, 2018; Marshall et al., 2021; Schwandt, 2014). The participants reviewed and verified the transcriptions of the interviews for accuracy and provided reactions, reflections, or corrections. Based on the participants' feedback, the transcripts were adjusted. In addition, each participant reviewed a summary of the analysis. We utilized multiple data sources to gain comprehensive and credible understandings and interpretations.

Findings

Through the re/telling of Joseph’s life story, past events, and memories, the participants interpreted Joseph’s identity and the impact this relationship had on their family and individual lives. The family narrative demonstrates how their understanding of disability shifted over time, both responding to and differing from the historical academic research and/or socio-political changes enacted during the 1960s and forward. Joseph’s life spans 60 years, and the language used to describe Joseph’s disability within the family narrative will reflect the language and knowledge of that period. This section is organized into Joseph’s birth story and diagnosis (early 1960s), childhood and education (1970s), adult life, and family’s reminiscence on life following the death of Joseph.

Beginning of the Life Journey

Joseph's birth in 1961 predated routine prenatal testing and current DNA testing that can definitively diagnose Down Syndrome. As an experienced mother, Nancy raised five children before Joseph and had concerns about her newest baby's development. While Down syndrome was suspected at Joseph's first check-up, doctors could not agree on whether Joseph had Down syndrome until he was 14 months old. Nancy wrote several reflective essays during this period of uncertainty and eventual diagnosis, which she described as a "very depressing time."

Nancy described her reaction to Joseph's diagnosis with raw emotion, revealing a deep sense of tragedy and shame around his disability:

> when the doctor blurted out, "he's Mongoloid [*sic*]." By his choice of words, the doctor inadvertently conveyed to me the idea that my son was less than human since a whole separate classification has been established to accommodate the likes of him . . . A non-rational feeling, perhaps but very real, nevertheless. Consequently, during those first few months, while Joseph himself established his own humanity by being exactly like any other cuddly infant, I had to struggle with my own repulsion towards him and toward myself for having produced this presumably nonhuman creature.

Once the diagnosis came, the pediatrician's prediction about Joseph's development was dire. Lindsey, Joseph's eldest sister, recalled that the doctors "expected him [Joseph] to be basically a vegetable." As was the common practice of the time, the doctors recommended that he be institutionalized. Nancy and Matt, Joseph's parents, were advised to consider the needs of their other children, the possible detrimental effects on them if Joseph remained in the household, and to prepare the other children for the possibility of Joseph being sent to live elsewhere if he "gets too hard to take care of."

Joseph's eldest sister, Lindsey, vividly remembered the day her mother, Nancy, told her that Joseph had "mental retardation [*sic*]." Both Nancy and Lindsey cried, and they vowed to teach Joseph as much as possible so he wouldn't be "retarded [*sic*]." The older siblings recalled a very strong adverse reaction to the idea that their brother might be sent away to live elsewhere.

In the early years of Joseph's life, having little experience with disability or support, Nancy wrote that her biggest concern was whether or not she would be able to love Joseph and respond to him:

> I never had any experience with anybody, I had never met anybody, I did when I was a little girl. I used to play with a little girl who was retarded [*sic*], . . . but that was all of the experience. And I used to worry about – I guess I felt I would reject him.

Consequently, Nancy had an almost compulsive need to watch Joseph, "looking for a sign that he was normal."

Despite the family's initial protest of the idea of institutionalization, they were encouraged to fill out the paperwork at least to register him and get on the waiting list. At the doctor's urging, Nancy took the papers but wrote of the emotional weight they put on her, "they used to be in that yellow chest of drawers, and every time I walked by there, I was so conscious of those papers being there. I couldn't fill them out." Eventually, after 2 years of stalling, Nancy filled out the papers. As a precautionary measure, Nancy and Matt visited one of the state institutions in California. In one of the written journals, Matt shared his reaction to the recommendation of the "experts":

> All the time we did it, we felt that was just "no,"not even a hesitation or any

> consideration of institutionalizing him. In fact, I felt very bad when we went out there to see the condition of the kids who were living there.

Based on these observations, the final decision was made that Joseph would stay at home.

Thankfully, more families of children with disabilities were also making the decision to parent their children and to support one another (Baglieri, 2022). While the label Mongoliod [*sic*] was an appropriate term for the diagnosis at that time, Nancy continued to struggle with the term for many years until she met another mother who had a daughter with the same disability as Joseph. Nancy writes of this support:

> "she gently informed me that the preferred term was Down syndrome. This knowledge freed me from the burden of having to use the detested expression. I am certain that had the doctor used the words 'Down syndrome' in relation to Joseph, much anguish could have been avoided. And yet the term Mongoloid [*sic*] still lives on carrying with it age-old erroneous stereotypes."

First Hint of Resistance

Through the family's historical writing and recollections from this early period in Joseph's life, the negative discourse around disability and giving birth to a child with a disability, and labels, the family's internal conflict can be seen. With their first-hand experience, Nancy and Matt, provide the first critique of the most common treatment of people with disabilities and reject the expert knowledge.

The research published during the 1960s viewed intellectual disability as an extensive threat to the family unit. The idea that the presence of children with disabilities damaged families came to dominate the field of family research in the second half of the 20th century (Ferguson, 2021). Adams (1967) put it this way: "Because of its adverse social consequences, mental retardation [*sic*] has to be viewed as a total family handicap and clinical treatment must therefore be geared toward protecting the healthy members from the potentially harmful effects" (p. 311). The risks included emotional neglect resulting from an intense focus on the disabled child, distorted family relationships, reduction of social contact, and increased anxiety and depression (Adams, 1967; Gath, 1973; Kaplan & Colombatto, 1966). Adam (1967) provided an ominous warning, "They (the siblings of retarded children) may grow up as warped in their capacity for self-fulfillment as the retarded [*sic*] child is" (p. 311). Despite existing literature predicting dire outcomes and the fact that few supports were available to families who had children with disabilities, Nancy and Matt resist this view of Joseph and their family.

Formal and Informal Childhood Education

Joseph's childhood occurred during the 1960s, in the wake of the civil rights movement in the United States. The civil rights movement had a significant effect on other socio-political movements, including the disability rights movement that began in the 1970s (Baglieri, 2022). Additionally, in 1972, a series of exposés on the Willowbrook State School in New York City brought public attention to the conditions within the institutions, giving rise to the deinstitutionalization movement (Baglieri, 2022). However, in 1970, only one in five children with disabilities were educated in US schools, and many states had laws that excluded children with intellectual disability (US Department of Education, 2024). Despite the lack of educational opportunities during that time period, Joseph's earliest education was actually integrated. Nancy taught at a progressive preschool in their city and took Joseph to work with her. Additionally, the siblings remember their mother going out of her way to be very explicit in teaching and providing learning opportunities.

During Joseph's early elementary school years, he began to attend a segregated special education school. The family described his experiences as a "mixed bag," with some empathic but often ill-prepared teachers offering a rather punitive and basic education.

Contrary to the research that warned that raising a child with a disability would restrict extra-familial activities and mobility (Gath, 1972), Joseph's family traveled widely. In 1970, the family traveled to Europe in a Volkswagen bus for 15 months. Joseph was 9 years old. During that period, he attended a child-centered school for children with disabilities in England, which his sisters described as an eye-opening educational experience for the family. Traveling in different countries provided a breadth of experiences for all of the siblings, and they each reflected on how Joseph was received during their travels. Kevin was just a year older than Joseph and recalled their experience: "It was just Joseph and me going off alone, going to the playground in the campground, or going around the museum. We used to walk with our arms around each other's shoulders." He recalled the reactions they received from people in Western Europe:

> It was really amazing to me that everybody just knew he was a wonderful person…
>
> I did not know anything about Down syndrome, and I just thought, 'Wow! Joseph is just such an exuberantly wonderful person that people can just recognize that.' They would come up and give him gifts and wave and smile at Joseph. It took me a long time to figure out why people everywhere knew that he had Down syndrome. I was looking at him, and he was just Joseph.

Kevin did not see the distinction that was obvious to others. It took Kevin a long time to recognize how people knew Joseph had Down syndrome. Kevin's lived experience differed from what was reflected in the sibling research of the period, which warned that siblings of individuals with intellectual disability may have negative experiences, such as feeling embarrassed, and affected social development and friendships (Kaplan & Colombatto, 1966; Gath & Gumley, 1987). The older siblings recognized the stares Joseph had received while in Eastern Europe but stated that they did not feel intimidated or embarrassed. In an interview during Kevin's adolescence, when asked to reflect on Joseph's disability, he said, "it's just like a difference, but not necessarily a handicap or anything."

Adolescence and Young Adulthood

During Joseph's adolescence, the US experienced radical changes in the educational rights of children with disabilities. Joseph was 14 years old when the Federal law, Education for All Handicapped Children's Act of 1975 was enacted (US Department of Education, 2024). For the first time, all children with disabilities were guaranteed the right to a public education. Joseph lived in a location that was better prepared than most to respond to the new educational law. Even though he attended special education classes at his local high school, all students were integrated and expected to participate in all typical high school social events like prom and graduation. Joseph's family had high expectations for him, and these new educational opportunities provided Joseph with a context and expectation to live a typical lifestyle, including work, dating, and an active social life.

Family Reflections and Shifting Understanding

In the early 1980s, Joseph's college-age sister, Catherine, encountered research on the detrimental effects of having a child with Down syndrome raised with the family, which differed from her and her family's lived experience. Thus, as a part of her sociology class project, Catherine had multiple conversations with her family members and documented their perspectives and experiences. This class project, which was conducted after living for nearly two decades as a family unit, captured the family's shifting perceptions of disability, labels, and intelligence. It signified a growing critique of ableism and discrimination against people with disabilities.

During one of the conversations Catherine had with her mother, Nancy, Catherine asked her mother if she ever worried about any detrimental effects on the family as a result of Joseph's disability. Nancy shared:

> Sometimes I wonder what life would have been like for Kevin if he didn't have a retarded [*sic*] brother because he shared a room with him, and he was responsible for him in a lot of ways. I keep wondering if it has affected him in some way. . . I think it's been really good for the rest of the kids; I think it has been a positive experience.

Catherine's own reflections indicate a general pride in Joseph. "All the siblings were proud of him. It's been, sort of, another thing that makes our family special compared to other families. I don't even recognize the idea that people could be alarmed by him. I think they'll love him."

During one of the conversations Catherine had with her father, Matt, he reflected on the meaning and importance of intelligence:

> I think Joseph has given me something to think about . . . an understanding of – a way of looking at intelligence and the importance of intelligence in a very different way. It has put it in perspective for me. And I think prior to that, I thought intelligence was the ultimate value or importance in an individual.

Kevin, then 18, who was one year older than Joseph, shared,

> We always used to play. I think we were just little brothers . . . I am really glad that I've had the chance to have a little brother like him. Just because of his whole different outlook on life. It gives me a lot of chances to think about how much intelligence matters and whether a deviation from the norm is a bad or good thing.

In one of the reflections, Joseph's mother began questioning the power of labels and prejudice and provides a glimpse of Joseph's resistance to the label. She recalled a phone conversation where she casually used the term retarded when referring to Joseph. She recalled in her writing the powerful reaction that Joseph had to this term following the end of the call demanding that she never use that word again.

> "Don't you ever say that again! Don't you ever, ever, ever say that again!" he (Joseph) said with all the intensity he could muster.
>
> I felt heartsick at Joseph's reaction. I chastised myself for not anticipating the possibility the term retarded [*sic*] spoken so casually could be a source of pain to him. I actually had assumed him to be unfamiliar with the word and its conceivably negative connotation. Questions arose in my mind – How

> did Joseph learn about the word? What pictures did it conjure up for him?

Nancy continued considering the terms, language, and prejudices associated with disability.

> Only a short time has elapsed since retarded [*sic*] individuals were allowed out of the institution and back bedrooms where they were kept hidden from the rest of society. That they now mingle with others is due largely to the efforts of parents and dedicated professionals who, through personal experience, had come to recognize that commonly held stereotypes about retardation were erroneous, that given an encouraging environment, mentally handicapped [*sic*] people could develop far beyond the limits previously assigned them. Yet, old attitudes change slowly… The description, retarded [*sic*], is a powerful one. It has the ability to render invisible all other characteristics in an individual.
>
> From my perspective as the parent of a mentally handicapped [*sic*] child, the problem of retardation [*sic*] lies in many respects less with Joseph than it does with the so-called "normal" person, for that person has something Joseph lacks, mainly power. With that power yields both singularity and collectively through institutions, he can determine the precise quality of life Joseph will be allowed to lead. Indeed, as recent events have demonstrated, he has that ultimate power, the power of life and death over the likes of Joseph. And yet, often, this power is exercised in complete ignorance and prejudice.

Within Nancy's reflection, there was a growing awareness and critique of the commonly held and medicalized view of disability, which limited the focus to the individual. Through her experiences, she was able to see how society further disabled individuals like Joseph through stereotypes and prejudice.

Living with Joseph challenged the family's values, priorities, and stereotypes of disability. While Nancy's initial view of disability was one of tragedy, she now acknowledges Joseph's personhood, gifts, and contributions to the family and stated, "he just generally enriched all of our lives." One of Nancy's essays described Joseph's social and emotional intelligence and his supportive role within the family unit.

> (Joseph) has a startling sensitivity to the feelings of others. I have discovered that while I am able to conceal my emotions from other family members, I cannot fool him. If I'm distressed, Joseph will pick up on my mood and bring it into the open with probing questions. He acts upon his intuition by providing an extra measure of support by means of a hug or kiss. What marvelous therapy he dispenses!

During the interviews with one of the researchers, the siblings recalled a particularly difficult period that their older sister experienced during her adolescence. Nancy also wrote about this period in their family life and Joseph's role.

> Once, during my daughter's tumultuous adolescence, her calculatingly hateful behavior managed to alienate everyone. None of us, neither mother, father, sister, or brothers, could cross the mountains of our own resentment and make contact – no one, except Joseph. Although he was well aware of the unpleasantness that had precipitated everyone's rejection, he sensed his sister's great loneliness and ignored the collective judgment, comforting her with hugs

> and words of love. This open display of affection, despite all, released the tears imprisoned behind his sister's sullen, defiant mask, and soon we were a whole family again. This scene, with variation, was repeated over and over again with each of our children.

Joseph's father also reflected on Joseph as a role model:

> There are qualities that Joseph has that are a model for me – I wish I had some of the spontaneity and some of them, oh, joy out of life, and some of the qualities . . . that if I wanted to get very philosophical about it, it could give me some things to think about in terms of the goals of life for people. Although he has a dependency on other people, and a vulnerability that is a problem for him, I certainly would like to capture for myself, some of the qualities he has. . . I think I could say that he's taught us all to love more.

As Joseph became a well-established member of the family, Down syndrome became less of a defining feature of his identity. His relational identity, personhood, and role in the family became his primary identity.

Adult Life and "Calling His Own Shots"

Following high school, Joseph attended a newly developed, progressive transition program focused on employment and independent living skills. In the 1980s, when the independent living movement had begun to include those with intellectual and developmental disabilities, Joseph graduated from the transition program. Community support for people to live in their own homes drastically increased. The research of the time period developed a more psychosocial approach (Ferguson, 2021), evaluating family resiliency, and how families coped with the stress of raising children with disabilities (Dyson & Fewell, 1986 McCubbin et al., 1980). The underlying assumption was that family stress was a result of the disability (Wikler, 1986). However, there was also an increase in narrative family research done by families themselves (Ferguson & Asch, 1989).

Nonprofit organizations funded by the State of California began to provide support to adults with intellectual disability to live and work in the community in an effort to reduce institutionalization. Joseph was a recipient of these services and moved into his own apartment. Catherine described Joseph as a "pioneer," or "a poster child" for the movement. With support from a supported living and employment agency which assisted him with budgeting, medical appointments, and learning new employment tasks, Joseph thrived. Joseph secured a job at a local restaurant, initially with the support of a job coach, and in time, worked independently. He proudly worked for a local restaurant for 30 years before his well-earned retirement. Lindsey, Joseph's second sister, stated that he liked to have a consistent routine and "calling his own shots."

Eventually, when most of the family members moved to other parts of California or out of state, Joseph decided to stay in his home community and work. He lived in his own apartment and had a long-term romantic relationship. Only Kevin remained in the local area. Joseph had an active adult social life and enjoyed spending time with his fiancé, Tina. In his midlife, Joseph lost his mother to cancer, but Joseph remained close to his father, his siblings, and their growing families through extended phone calls and spent extended time with them during the holidays.

Several of Joseph's nieces and nephews requested to be interviewed for this research, indicating his significant role in family gatherings and their lives. When asked to describe their uncle, they stated that "he was a man's man," "He loves sports," and "He was competitive and imaginative. Joseph's niece, Rachel, a singer and performer, connected with Joseph around music. She stated that he loved to listen to his Walkman player and sing along, "very loudly." When describing his fearlessness to show off his dance moves and his love for John Travolta, Rachel stated "he was guileless, he just would go for life and was not hung up a lot by appearances." Remembering Joseph's sense of imagination, she recalled him whipping out his magic scissors to open tightly wrapped Christmas presents. Rachel stated, "Uncle Joseph was a big presence in our lives,"

Joseph shared his love for sports with his nephews, and they mentioned that Joseph was "the most stereotypically male of the bunch." Joseph loved collecting baseball cards, was competitive, and was a dedicated Angels fan. According to Joseph, despite the actual score of the game, the Angels were always winning. On holidays when Joseph visited, he would play football and basketball with his three nephews and brother-in-law.

Like some of the current sibling research, which focuses on some of the positive outcomes for nondisabled siblings (Hodapp & Urbano, 2007; Hodapp, et al. 2010; Macks & Reeve; 2007; Tomeny et al., 2017), the niece and nephews reported being more attentive, careful with the use of negative labels, and protective of those with disabilities due to their positive relationship with their uncle. Joseph's nephew, Tyler, attributed this relationship to his development of empathy for others. Rachel felt she developed an enjoyment for caretaking and an acceptance of people with any form of difference.

Aging

When Joseph was born in the 1960s, the average life expectancy of individuals with Down syndrome living in an institution was ten years. In 1984, it increased to 28 years; today, the average life expectancy is approximately 60 years (Chicoine, 2023, Centers for Disease Control, 2023). Many individuals with Down syndrome experience accelerated aging, resulting in the early onset of some illness, including Alzheimer's disease (National Down Syndrome Society, 2023). Additionally, Alzheimer's disease affects individuals with Down syndrome at a higher rate than the general population (National Down Syndrome Society, 2023). Unfortunately, in this regard, Joseph's experience did align with the research.

After working for a single employer for nearly 30 years, Joseph decided to retire from work in his early 50s. He eventually moved to Northern California near his eldest sibling, Lindsey, but he wanted to have his own place. He continued to live independently with the support of a new nonprofit organization and reestablish a life in a new community. At age 56, however, he was diagnosed with Alzheimer's. Lindsey coordinated his end-of-life support, but all siblings shared different levels of responsibility. Even as Joseph's health declined, Joseph's siblings continued to honor his desire to live in his own home, outside an institutionalized life. He was able to die at home with his family with him.

Reminiscing on Life after Joseph's Death

This research was conducted approximately 1 year after Joseph's death. The siblings reflected a sense of pride in how each member worked as a cohesive family during the last years of Joseph's life with Alzheimer's disease. Kevin shared that "we really pulled together to give him (Joseph) what he needed, and he gave us a wonderful experience,"

Joseph was not the only beneficiary of care and support from his non-disabled family members. His non-disabled family members also described how they benefited from this relationship. Multiple family members spoke of Joseph as a role model and teacher. The siblings explained that Joseph "had more confidence than any of the rest of us" and anybody they ever met. Joseph's oldest sister, Lindsey, acknowledged that Joseph "was the most grounded and confident and happy person I've ever met. Joseph was a great role model in that way." Joseph's brother, Kevin, also spoke of Joseph as a grounding source in his life:

> He was a central figure in my life. I think I would be a lot different if I hadn't had Joseph in my life or if he was, God forbid, in an institution. He helped me to see the value of family, of caring for people … you know, maybe it had to do with me becoming a doctor and really resonating with being a family doctor. I think there are probably multiple impacts in terms of the idea of helping others and not just doing things for yourself.

Joseph loved pop culture, and his siblings remarked on his ability to mimic others' mannerisms and dance without guile. His siblings admired his ability to have fun with the simplest things, even envying him and his positive outlook on life. Kevin shared:

> He would take his underwear, not the boxer but the briefs: and he put them over his head, and he would become a deep-sea diver . . . It was fun to tease him about it because he remembered it, and then he would deny that he'd ever done that. But I have many fond memories . . . He was very creative.

Kevin shared, and other siblings also agreed,

> I think Joseph was one of the most important people in my life. He did help to ground me in terms of that feeling of responsibility and pride that I could play an important role in his life and, you know, be around him. It was just such a pleasure and honor almost to have that relationship with him that I think (Joseph) helped make me who I am.

Discussion

This case study spans a period of 60 years and provides a means to examine the progress made in supporting people with disabilities and also to challenge negative assumptions about the lives of people with Down syndrome and their families. In many ways, the provisions and expectations for people with intellectual disability have drastically changed. Thanks to advocacy, civil rights efforts, and the passage of significant federal laws that targeted discrimination against people with disability, the opportunities afforded those with intellectual disabilities in the United States have increased. The majority of people with intellectual disabilities now grow up with their families and within the larger community, either living with family members or in their own homes (Hewitt and Stancliffe, 2013), allowing family and supporters to experience long-term relationships with people with intellectual disability. Essential to positive quality-of-life outcomes are inclusive educational opportunities (Kefallinou et al., 2020) and strong transition planning to personalized vocational and community support (Mellard & Lancaster, 2003). Unfortunately, there remain great disparities regarding the quantity and quality of these supports and opportunities in the United States (Hewitt and Stanclife, 2013).

Despite advancements, deficit views of disability continue to dominate our cultural understanding of intellectual disability. While a total of 187 countries have committed to inclusive education by signing the Convention of the Rights of Disabled Persons, negative attitudes about disability continue to impede full implementation

(Mitchell & Sutherland, 2020). Integrated employment opportunities remain elusive for adults with developmental disabilities. Legislation and incentives targeted at providing employment opportunities for individuals with disabilities have had limited impact and only 35% of individuals with disabilities are employed (Bonoccio et al., 2019). Bonoccio (2019) cited pessimistic thinking about the ability of individuals with disabilities as a major factor in underemployment. Discrimination toward people with intellectual disabilities and in particular individuals with Down syndrome is evidenced by attempts to eradicate Down's syndrome through prenatal testing and selective abortion. Countries such as Iceland and Denmark currently prevent the birth of nearly 100% of babies who have been diagnosed prenatally with Down's syndrome (Burke, 2021). The desire to terminate these lives is fueled by deficit-led conceptions of disability (Kittay, 2017) and justified by the "imagined suffering of the not yet born disabled child but also crucially the imagined suffering of the family of that child" (Burke, 2021, p. 196). While this single case study cannot be generalized to the experience of all families with a disabled member, it does add to the body of family research that challenges the framing of disability entirely in terms of "deficit, difficulty, parental disappointment, and struggle" (Burke, 2021, p. 193) and asserts to positive and caring family outcomes (Orsmond & Seltzer, 2007; Skotko & Levine, 2006).

Contrary to many research studies that continue to focus on the risks that siblings of individuals with disabilities face (Hayden et al., 2019), the participants in this study spoke almost entirely about the positive impact that Joseph had on their lives. Having little experience with disability, Joseph's parents initially experienced Joseph's diagnosis as a family tragedy and feared that Joseph's disability would negatively impact him and the family system. This perspective on disability reflected the prevailing cultural attitude toward disability and the medical model of disability. Their lived experience, however, challenged this perspective. The data demonstrates a shift in their language from deficit to asset, burden to benefit, and disability focus to a relational identity. As this transformation occurred, the family began to actively critique ableism and to identify ways in which negative attitudes toward those with intellectual disability further impaired individuals. This shift in perspective aligns with the social model of disability and the disability rights perspective.

Sibling relationships are some of the longest-lasting relationships, as they typically outlive the parents (Burbidge & Minnes, 2014). The findings from this study illustrate a close family relationship between non-disabled and disabled siblings and are consistent with other family research (Burbidge & Minnes, 2014; Chase & McGill, 2019; Skotko & Levine, 2006). Additionally, consistent with other research that found siblings often assume an informal carer role in adulthood (Cuskelly, 2016), Joseph's siblings anticipated remaining an active part of Joseph's support. Like many parents of children with disabilities, as Joseph's parents aged, they expressed concern for Joseph's care and the impact this may have on the non-disabled siblings. However, as community services such as supported employment and supported living services increased during Joseph's life, he had the opportunity to remain close to his family but not directly dependent on family members for routine day-to-day care until the last years of his life when his Alzheimer's symptoms increased. Joseph and his family's experiences demonstrate the positive effect quality community services can provide and should motivate us to continue to strive for personalized educational, vocational, and community support for individuals with disabilities and their families through adult life.

Conclusion

Joseph and his family's life story provides a multigenerational perspective and counter-narrative to the medical view of disability that often defines people by a condition, views disability in terms of tragedy and burden, and their families as "at-risk." The family's eulogy and reflection on Joseph's life provide a sharp contrast to his birth story and the medicalized view of his potential life and identity. One cannot help but contrast the fullness of Joseph's life and the impact of this life with those of his institutionalized peers who lived unseen lives and whose death is marked only by numbered, nameless gravestones (California Department of State Hospitals, n.d.). This family's lived experience attests to a rich, reciprocal relationship no longer largely defined by disability but by Joseph's unique personality, outlook on life, and personhood.

As we consider the 6 million children worldwide who continue to live institutional lives (Goldman et al., 2020), and those whose lives will be prevented, the final words from Joseph's eulogy may provide a glimpse of what could be:

> Having Joseph as a member of our family was a great gift, and we are happy that we helped him live life on his terms and to the fullest extent possible. Joseph was the happiest and most self-confident person we know. He taught us that living a rich, kind, and loving life is the end goal, intellectual ability is insignificant, family is everything, and John Travolta rules.

References

Adams, M. E. (1967). Siblings of the retarded: Their problems and treatment. *Child Welfare*, *46*(6), 310–334. http://www.jstor.org/stable/45399863

Baglieri, S. (2022). *Disability in the inclusive classroom.* Routledge.

Bekkema, N., de Veer, A. J., Hertogh, C. M., & Francke, A. L. (2015). 'From activating towards caring': Shifts in care approaches at the end of life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians. *BMC Palliative Care, 14*(33), 1-10. https://doi.org/10.1186/s12904-015-0030-2

Bogdan, R., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theory and methods*. Allyn and Bacon.

Bonaccio, S., Connelly, C.E., Gellatly, I.Rm ., Jetha, A., & Ginis, K. (2020). The Participation of people with disabilities in the workplace across the employment cycle: Employer concerns and research evidence. *Journal of Business and Psychology, 35,* 135–158. https://doi.org/10.1007/s10869-018-9602-5

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Burbidge, J., & Minnes, P. (2014), Relationship quality in adult siblings with and without developmental disabilities. *Family Relations, 63*(1), 148-162. https://doi.org/10.1111/fare.12047

Burke, L. (2021). Hostile environments? Down's syndrome and genetic screening in contemporary culture. *Medical Humanities, 47,* 193-200. https://doi.org/10.1136/medhum-2020-012066

California Department of State Hospitals (n.d.). *The California memorial project*. https://www.dsh.ca.gov/Hospitals/California_Memorial_Project.html

Chase, J., & McGill, P. (2019), The Sibling's perspective: Experiences of having a sibling with a learning disability and behaviour described as challenging. Tizard Learning Disability Review, 24 (3), 138-146. https://doi.org/10.1108/TLDR-11-2018-0032

Centers for Disease Control and Prevention. (CDC). (2023, June 28). *Data and statistics on Down syndrome.* https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html#:~:text=The%20life%20expectancy%20of%20people,be%20about%2047%20years%20old.

Chaiken, S. R., Mandelbaum, A. D., Garg, B., Doshi, U., Packer, C. H., & Caughey, A. B. (2023). Association Between Rates of Down Syndrome Diagnosis in States With vs Without 20-Week Abortion Bans From 2011 to 2018. *JAMA network open*, *6*(3), e233684. https://doi.org/10.1001/jamanetworkopen.2023.3684

Chicoine, B. (2023). *Aging and life expectancy*. Adult Down Syndrome Center. https://adscresources.advocatehealth.com/resources/aging-and-life-expectancy/

Creswell, J. W., & Guetterman, T. C. (2018). *Educational research* (6th ed.). Pearson.

Cuskelly, M. (2016). Contributors to adult sibling relationships and intention to care of siblings of individuals with down syndrome. *American Journal on Intellectual and Developmental Disabilities*, *121*(3), 204–218. https://doi.org/10.1352/1944-7558-121.3.204

Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body.* Verso.

Dyson, L., & Fewell, R. R. (1986). Stress and adaptation in parents of young handicapped and nonhandicapped children: A Comparative study. *Journal of the Division for Early Childhood, 10(*1), 25–35. https://doi.org/10.1177/105381518601000103

Farber, B. (1963). Interaction with retarded siblings and life goal of children. *Marriage and Family Living, 25,* 96-98.

Ferguson, P. (2001). Mapping the family: Disability studies and the exploration of parental response to disability. *In Handbook of Disability Studies* (pp. 373-395). SAGE Publications. https://doi.org/10.4135/9781412976251

Ferguson, P. M., & Asch, A. (1989). Lessons from life: Personal and parental perspectives on school, childhood, and disability. *Teachers College Record*, *90*(6), 108-140. https://doi.org/10.1177/016146818909000606

Ferguson, P. M., & Nusbaum, E. (2012). Disability studies: What is it and what difference does it make? *Research and Practice for Persons with Severe Disabilities, 37*(2), 70-80. http://www.iimhl.com/files/docs/20150415a.pdf

Ferri, B. A., & Connor, D. J. (2006). *Reading resistance: Discourse of exclusion in desegregation & inclusion debates.* Peter Lang Publishing.

Gabel, S. L., & Kotel, K. (2018). Motherhood in the context of normative discourse: Birth stories of mothers of children with Down syndrome. *Journal of*

Medical Humanities, 39, 179–193 https://doi.org/10.1007/s10912-015-9367-z

Galvin, K. T, .& Prendergast, M. (2016). Introduction. In *Poetic inquiry II: Seeing, understanding, caring: Using poetry as and for inquiry* (pp. xi-xvii). Springer.

Gath, A. (1972). The mental health of siblings of congenitally abnormal children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *13*(3), 211–218. https://doi.org/10.1111/j.1469-7610.1972.tb01146.x

Gath, A. (1973). The school age siblings of Mongol children. *British Journal of Psychiatry, 123* (573), 162-167.

Gath, A., & Gumley, D. (1987). Retarded children and their siblings. *Journal of Child Psychology and Psychiatry*, *28*(5), 715–730. https://doi.org/10.1111/j.1469-7610.1987.tb01554.x

Goldman, P. S., Bakermans-Kranenburg, M. J., Bradford, B., Christopoulos, A., Ken, P., Cuthbert, C., Duchinsky, R., Fox, N. A., Grigoras, S., Gunnar, M. R., Ibrahim, R. W., Josephson, D., Kusumaningrum, S., Agastya, N., Mwangangi, F. M., Nelson, C. A., Ott, E. M., Reijman, S., van IJzendoorn, M. H., … Sonuga-Barke, E. (2020). Institutionalisation and deinstitutionalisation of children 2: Policy and practice recommendations for global, national, and local actors. *The Lancet: Child & Adolescent Health, 4*(8), 606–633. https://doi.org/10.1016/S2352-4642(20)30060-2

Hayden, N., Hastings, R. Totsika, V., & Langley, E. (2019) A Population-based study of the behavioral and emotional adjustment of older siblings of children with and without intellectual disabilities. *Journal of Abnormal Child Psychology, 47*(8), 1409 –1419. https://doi.org/10.1007/s10802-018-00510-5

Hewitt, A. S., Stancliffe, R. J., & Emerson, E. (2013). Community living and participation: embracing the complexity and forging forward. *Intellectual and Developmental Disabilities*, *51*(5), 423–427. https://doi.org/10.1352/1934-9556-51.5.423

Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research, 51*, 1018-1029. https://doi.org/10.1111/j.1365-2788.2007.00994.x

Hodapp, R. M., Urbano, R. C., & Burke, M. M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities, 48*(1), 52–62. https://doi.org/10.1352/1934-9556-48.1.52

Kaplan, F., & Colombatto, J. (1966). Head Start program for siblings of mentally retarded children. *Mental Retardation, 4*(6), 30-32.

Kefallinou, A., Symeonidou, S. & Meijer, C.J.W. (2020). Understanding the value of inclusive education and its implementation: A review of the literature. *Prospects* 49, 135–152. https://doi.org/10.1007/s11125-020-09500-2

Kittay, E. F. 2017. How not to argue for selective reproductive procedures. *Kennedy Institute of Ethics Journal* 27 (2): 185–215. https://doi.org/10.1353/ken.2017.0015.

Landsman, G. (1998). Reconstructing motherhood in the age of 'perfect' babies: Mothers of infants and toddlers with disabilities. *Signs, 24*(1), 69-99.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York University Press.

Macks, R. J., & Reeve, R. E. (2007). The Adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, 37(6), 1060–1067 (2007). https://doi.org/10.1007/s10803-006-0249-0

Marshall, C., Rossman, G. B., & Blanco, G. L. (2021). *Designing qualitative research* (7th ed.). Sage.

McCubbin, H. I., Joy, C. B., Cauble, A. E., Comeau, J. K., Patterson, J. M., & Needle, R. H. (1980). Family stress and coping: A decade review. *Journal of Marriage and the Family, 42*(4), 855–871. https://doi.org/10.2307/351829

Mellard, D. F., & Lancaster, P. E. (2003). Incorporating adult community services in students' transition planning. *Remedial and Special Education*, 24(6), 359-368. https://doi.org/10.1177/07419325030240060701

Mitchell, D., & Sutherland, D. (2020). *What really works in special and inclusive education: Using evidence-based teaching strategies (3rd ed.).* Routledge. https://doi.org/10.4324/9780429401923

National Association for Down Syndrome. (NASDS;n.d.-a). *Facts about Down syndrome.* https://www.nads.org/resources/facts-about-down-syndrome/

National Association for Down Syndrome. (NASDS; n.d.-b). *History of NADS.* https://www.nads.org/about-us/history-of-nads/

National Down Syndrome Society. (2023). *Aging and Down syndrome: A Health and well-being guidebook.* https://ndss.org/resources/aging-and-down-syndrome-health-well-being-guidebook

National Institute on Aging. (2020). *Alzheimer's disease in people with Down syndrome*. https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome

Oliver, M. (1996). *Understanding disability: From theory to practice.* Macmillan. http://dx.doi.org/10.1007/978-1-349-24269-6

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: effects on adult lives. *Journal of Intellectual Disability Research, 51,* 682-696. https://doi.org/10.1111/j.1365-2788.2007.00954.x

O'Neill, L. P., & Murray, L. E. (2016). Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses. *Research in Developmental Disabilities*, *51-52*, 116–125. https://doi.org/10.1016/j.ridd.2015.12.017

Prendergast, M. (2009). "Poem is what?" Poetic inquiry in qualitative social science research. *International Review of Qualitative Research, 1*(4), 541-568. https://www.jstor.org/stable/10.1525/irqr.2009.1.4.541

Redquest, B. K., Tint, A., Ries, H., Goll, E., Rossi, B., & Lunsky, Y. (2020). Support needs of Canadian adult siblings of brothers and sisters with intellectual/developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 17*(3), 239-246. https://doi.org/10.1111/jppi.12339

Schwandt, T. A. (2014). *The Sage dictionary of qualitative inquiry* (4th ed.). Sage.

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation, 43*(5), 354–359.

Skotko, B. G., & Levine, S. P. (2006). What the other children are thinking: brothers and sisters of persons with Down syndrome. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *142C*(3), 180–186. https://doi.org/10.1002/ajmg.c.30101

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Self-perceptions from people with Down syndrome. *American journal of medical genetics. Part A*, *155A*(10), 2360–2369. https://doi.org/10.1002/ajmg.a.34235

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource.* Wiley.

Tomeny, T. S., Ellis, B. M., Rankin, J. A., & Barry, T. D. (2017). Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism. *Research in Developmental Disabilities*, *62*, 104–114. https://doi.org/10.1016/j.ridd.2017.01.008.

Trip, H., Whitehead, L., Crowe, M., Mirfin-Veitch, B., & Daffue, C. (2019). Aging with intellectual disabilities in families: Navigating ever-changing seas–A theoretical model. *Qualitative Health Research, 29*(11), 1595-1610. https://doi.org/10.1177/1049732319845344

US Department of Education. (2024). *A History of the Individuals with Disabilities Education Act.* https: //sites.ed.gov/idea/IDEA-History

Wagemans, A. M., Van Schrojenstein Lantman-de Valk, H. M., Proot, I. M., Metsemakers, J., Tuffrey-Wijne, I., & Curfs, L. M. (2013). End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliative Medicine, 27*(8), 765-771. https://doi.org/10.1177/0269216312468932

Wehmeyer, M. L., Brown, I., Percy, M. E., Shogren, K. A., & Fung, W. L. A. (Eds.). (2017). *A comprehensive guide to intellectual and developmental disabilities*. Paul H. Brookes.

Wikler, L. (1986) Periodic stresses in families of mentally retarded children: An exploratory study. *American Journal of Mental Deficiency 90*(6), 703–6.

Correspondence concerning this article should be addressed to Tammy Bachrach, Azusa Pacific University. E-mail: tbachrach@apu.edu.

Using the *Teach Your Child to Read in 100 Easy Lessons* Curriculum with a Child with Autism Spectrum Disorder

Sandra C. Yepez Haro and Jennifer Ninci
University of Hawaiʻi at Mānoa

Gregory G. Taylor
On to the Goal, LLC

Abstract: The Teach Your Child to Read In 100 Easy Lessons (TYCTR) curriculum incorporates evidence-based methods such as direct instruction and errorless teaching. This study was designed to extend research on the effectiveness of the TYCTR curriculum for increasing the acquisition of oral reading fluency among targeted basic vocabulary words. We used a multiple probe across units design with a child with autism spectrum disorder to measure the effectiveness of the curriculum's first 30 lessons. We divided lessons into ten units that included three lessons per unit. Results demonstrated the effectiveness of TYCTR for acquiring basic vocabulary words targeted within the curriculum. The participant did not read any of the 62 probed vocabulary words during baseline. The participant read all 62 words within a three-second latency by the end of the intervention. Future research should focus on completing all 100 lessons as opposed to just the first 30 lessons and increasing the external validity of the curriculum by continuing to focus on expanding the knowledge about the effectiveness of TYCTR for children with ASD and other developmental disabilities.

In a large sample of preschools in the United States, it was estimated that approximately 30% to 35% of children would begin their elementary education with delays in language and early literacy (Carta et al., 2015). Children between the ages of 2 and 5 years old with language delays are at a higher risk for increased difficulty with reading (McLaughlin, 2011). Children with autism spectrum disorder (ASD) experience social communication deficits and often fail to develop basic literacy skills (American Psychiatric Association, 2013; Connor et al., 2014). Many children with ASD warrant specialized, individualized, evidenced-based instruction in reading (Thompson, 2008).

A greater focus has been placed on early reading programs to address the challenges presented to individuals with difficulty reading (Denton, 2012). To identify effective reading instruction methods, the National Reading Panel (2000) researched evidence-based peer-reviewed literature. It found that effective reading intervention contains the following five key elements: phonemic awareness, phonics, vocabulary, reading fluency, and reading comprehension (National Reading Panel, 2000). *Phonemic awareness* refers to a reader's ability to identify and hear the smallest units of sounds. *Phonics* refers to the ability to demonstrate a relation between sounds and letters. *Vocabulary* refers to a reader's ability to understand word meaning. *Reading fluency* refers to the ability to read with speed and accuracy. Last, *reading comprehension* refers to the ability of a person to derive and understand meaning from a text. Approaches to reading instruction that focus on developing these key elements will likely improve reading outcomes (National Reading Panel, 2000).

Additional research has found direct instruction to be a highly effective method for teaching children how to read (Becker, 1977; McCollough et al., 2008). Increased evidence suggests that direct instruction is one of the most effective ways of teaching children with ASD to read as well (Rimmer et al., 2022; Tárraga-Mínguez et al., 2020). Direct instruction is a structured approach that involves scripts for the implementer and breaking down tasks into concrete steps of a sequence to promote acquisition (Tárraga-Mínguez et al., 2020).

Errorless teaching or learning is an effective method for teaching various skills to children with ASD (Mueller et al., 2007). Errorless teaching is a set of procedures designed to reduce incorrect responses as a learner reaches mastery. Errorless teaching methods have been used to effectively teach children a variety of tasks, such as the recognition of sight words, colors, numbers, and shapes (Mueller et al., 2007).

One reading curriculum with emerging evidence for success in improving student reading outcomes is *Teach Your Child to Read in 100 Easy Lessons* (TYCTR; McCollough et al., 2008; McConnell & Kubina, 2016). This approach employs direct instruction alongside errorless teaching procedures to improve reading skills (Engelmann et al., 1983). The TYCTR curriculum integrates key elements found by the National Reading Panel (2000), including phonemic awareness, phonics, reading fluency, and reading comprehension. The TYCTR curriculum is designed for parents to teach their children to read with an approach that builds non-readers up to the second-grade reading level (Engelmann et al., 1983). This intervention targets parents because they are typically their children's first teachers (McConnell & Kubina, 2016). It has also been suggested that this approach can be effective when administered by other interventionists in settings outside of the home (Johnson et al., 2001). Emerging research has demonstrated the effectiveness of the TYCTR curriculum in improving fundamental reading skills for children with reading difficulties. The curriculum is composed of 100 scripted lessons for implementers to follow. The lessons focus on phonemic awareness, phonics, and comprehension skills. Each lesson lasts an average of 20 minutes. The program is a cost-effective alternative to costly commercialized curricula (Johnson & Boyd, 2013).

Several studies have been conducted on the effectiveness of the TYCTR approach, resulting in a growing body of evidence supporting its use in teaching reading skills across various settings and populations. Empirical research on the curriculum's effectiveness has been conducted with several populations of children with or at risk for reading difficulties, indicating the children benefited from the curriculum through demonstrated progress in reading skills (e.g., Fjortoft et al., 2014; McCollough et al., 2008; McConnell & Kubina, 2016).

For instance, a study conducted by McCollough et al. (2008) evaluated the effectiveness of TYCTR with a 6-year-old female diagnosed with attention-deficit hyperactivity disorder (ADHD), cognitive disorder, and mixed receptive-expressive language disorder. The study was implemented by an experimenter in a university preschool, 4 days a week, and in the morning for 50 minutes. A multiple baseline design was conducted across target words and probe words to measure the effectiveness of TYCTR. Target words included words that were explicitly taught in the lessons. Probe words were not taught in the lessons but were composed of the sounds taught in the lesson. The results showed increased correct responses for both target and cold probe words. The study's authors recommended that TYCTR should be considered by special education teachers working with children with disabilities who lack decoding skills.

Additionally, McConnell and Kubina (2016) examined the effectiveness of TYCTR with three kindergarten students at risk for reading difficulties. The study examined the effects of the first 30 lessons of the TYCTR curriculum implemented by children's parents. The parents were asked to spend 15 minutes a night implementing the lessons at home, 5 days a week. They used a multiple probe design. The results showed that the children benefited from the intervention as they all demonstrated an increase in the words they could read.

While research with methodological rigor supports the use of TYCTR across various populations, published peer-reviewed literature does not yet include studies on the effectiveness of the TYCTR curriculum for children with ASD. The TYCTR curriculum is founded upon the instructional approaches of direct instruction and errorless teaching, both of which have evidence supporting the improvement of a variety of learning outcomes for children with ASD (Mueller et al., 2007; Tárraga-Mínguez et al., 2020). This study aims to increase the external validity of research on the TYCTR curriculum by expanding the knowledge about populations that may benefit from the approach. The purpose of this study was to measure the effectiveness of the TYCTR approach on the acquisition of basic vocabulary words by a child diagnosed with ASD. This study addressed the following question: When implemented with fidelity (i.e., over 80% accuracy), does TYCTR increase the acquisition of basic vocabulary words for a child diagnosed with ASD?

Method

This project was conducted as the focus of the first author's master's capstone research project. One participant for the study was selected based on convenience—the study was designed to be extended from the practice of the first author, who worked with the participant.

Participant

The participant in this study was Ryan, an 8-year-old African American boy diagnosed with ASD at the age of 2 and a developmental speech and language disorder at the age of 3. Ryan received 12 hours of applied behavior analysis (ABA) services outside of school and special education services at school. He received 30 minutes of speech therapy and 30 minutes of occupational therapy per week. Ryan's special education and general education teachers described him as below grade level in reading, and his reading activities were modified from the general curriculum activities.

Setting and Materials

The primary setting for this study was Ryan's home. Ryan lived with both his parents, 6-year-old sister, and maternal grandmother. He received ABA services 12 hours per week from a Registered Behavior Technician (RBT) in the home, supervised by a Board Certified Assistant Behavior Analyst (BCaBA), the implementer and first author of this study. The study occurred outside of regularly scheduled services for Ryan. The study was conducted in Ryan's upstairs covered balcony. The balcony was 400 square feet with two couches, four chairs, a coffee table, and a TV mounted on the wall. The study was conducted at the coffee table, with Ryan and the implementer sitting beside each other. The materials included the TYCTR book that includes all instructional lessons based on the Direct Instruction System for Teaching Arithmetic and Reading (DISTAR) Reading Mastery Fast Cycle (Engelmann & Bruner, 1977), 62 3x5 inch flashcards with printed target words, a timer, and an iPad to video record the session.

Design

We used a multiple probe across reading units design to analyze the relation between the effectiveness of TYCTR (independent variable) and the acquisition of oral reading fluency (dependent variable). The design was used to examine initial and ongoing levels of vocabulary reading fluency among vocabulary targets as the TYCTR curriculum was systematically applied across units. We used visual analysis within and between baseline and intervention phases, including analyses of changes in level, trend, and variability. We evaluated the consistency of data across similar phases.

Measurement and Operational Definitions

Oral reading fluency was measured by the number of words correctly read. The words were counted as correct if Ryan would read the word out loud, without individually sounding out each letter, taking no longer than 3 seconds. Any word read incorrectly and then self-corrected before a 3-second latency was marked as correct. A word was marked as incorrect if Ryan (a) added a word or letter to make a new word, (b) deleted a letter sound in the word, or (c) did not correctly pronounce the word within 3 seconds. The implementer collected data during the session while it was being recorded.

Procedure

The first 30 lessons of TYCTR were divided into 10 units, with three lessons in each unit. Implementing each unit, including lesson administration, probes, and breaks, lasted approximately 2 hours. Sessions occurred 3-5 days a week for approximately 3 weeks.

Breaks occurred between all lessons and probe sessions. During these 10-minute breaks, the implementer played a brief game with Ryan, such as chase or hide and seek, to provide time away from the academic demands and to reinforce ongoing participation.

To administer probes to assess student progress, the implementer used the following procedure: (a) hold up an index card with the word printed in lower case letters, (b) provide a cue by saying “read the word,” (c) put the card down after 3 seconds, (d) say “thank you,” and (e) hold up the next index card. The steps were repeated until there were no more words to probe. No error correction or feedback was given during probes, but Ryan was thanked for his effort after each probe, and 10-minute breaks followed each probe.

Baseline

During baseline, the implementer completed a whole word probe for all 62 words using the measurement procedures described above and recorded the number of words that Ryan read correctly. After a break following the first whole word probe, the implementer administered a series of unit probes that included only the words that would be targeted in a unit. The unit word probe was repeated three times or until there was a stable baseline. A stable baseline included no change in level, trendline, and variability for at least three data points. Once the baseline criteria were met for the unit word probe, the implementer progressed to the intervention phase for that respective unit. This baseline sequence of activities occurred for the remaining units.

Intervention

The implementer delivered 10 units, each with three grouped lessons, for a total of 30 lessons. Table 1 lists the criterion set words required for each unit. Each three-lesson unit was taught on different days. During the session, the implementer followed the script provided by the TYCTR curriculum for each lesson.

Table 1

Set Words for Each Unit of Instruction

Unit	Words in Unit	Cumulative Words
1	Am	1
2	Me	2
3	Mat, Sat	4
4	See, Ram, Eat, Rat, At, Seed, Sam, Seat	12
5	Sad, Mad, Meat, Read, Ear, Meet, It, Sit	20
6	Is, Seem, That, This, The	25
7	Mitt, Rid, Sack, Cat, Sick, Rack	31
8	Mom, Rod, Sock, On, Not, In, An, Can	39
9	Man, Ant, Near, Fat, Fan, Feet, If, And, Fin, Fun, Run	50
10	Mud, Sun, Fit, Feed, Nut, Land, Little, Fill, Lot, Lid, Lick, Sand	62
Total:		62

Note. Targeted words are from the *Teach Your Child to Read in 100 Easy Lessons* curriculum (Engelmann et al., 1983).

Lessons. Lesson lengths were variable. Each lesson followed a similar format, beginning with practicing the previously taught sounds or introducing a new sound. Each step had instructions on what to say and what to do. Curricular instructions in parentheses were what the instructor would do, while the words italicized were what they would say. Throughout the script, the words between quotation marks were what Ryan was expected to answer. If Ryan did not give the correct answer, then the implementer would use the error correction instructions that followed. In every lesson, the sound or word was taught right before Ryan was expected to answer. He was immediately corrected if he made an error or did not respond.

Probes. After a unit lesson break, the implementer administered two unit probes similar to baseline unit probes to assess the words learned during the unit. Before beginning the next unit of instruction on a new day, the implementer administered a third unit probe assessing student retention of the content of the previous unit, serving as a third measure of student performance. Ryan could move on to the next instruction unit after meeting the performance criterion of 100% for three consecutive probes. If Ryan did not meet the criterion for three consecutive probes, the previous unit was retaught for that session. If Ryan met the criterion of 100% for three consecutive probes, he continued to the next unit of instruction. Before beginning a new sequence of lessons in a session, the implementer administered a whole word probe assessing Ryan's knowledge of all 62 words, followed by a 10-minute break.

Interobserver Agreement

Sessions were video recorded to assess the reliability and procedural integrity. The implementer randomly selected 30% of videos to be viewed by a second observer. The second observer independently watched recordings and collected data. The second observer was a Board Certified Behavior Analyst (BCBA) trained in the data collection methods needed to complete the checks for interobserver agreement (IOA) and procedural integrity. The second observer's data on the probes was compared to the implementer's data to determine the percentage of agreement on the number of words read correctly. In the event of a disagreement within a session probe, the entire session was calculated as a disagreement. The number of agreements was divided by the total number of possible agreements and multiplied by 100 to obtain the percentage of IOA for each unit. The collection of IOA data occurred for Units 3, 5, and 9 (26% of total sessions). IOA data for each unit included the round of whole word probes and the pre- and post-intervention unit word probes; however, only the first three post-intervention data points included IOA.

The IOA scores were 100% for Unit 3, 86% for Unit 5, and 100% for Unit 9. There was specifically a disagreement about the word "read." The second observer counted it correctly as Ryan self-corrected; however, the first observer and implementer marked it as incorrect because Ryan had self-corrected after the 3-second latency had passed. The data collectors decided that if Ryan self-corrected after the 3-second latency had passed, they would not count it as correct.

Procedural Integrity

To assess the integrity of the implementation of TYCTR, the implementing first author developed an itemized checklist for the 30 lessons. Each lesson consisted of six to 14 different tasks, each with up to nine steps to follow. The same BCBA second observer who collected IOA viewed recordings for the same three units (i.e., Unit 3, Unit 5, Unit 9) to check for implementation accuracy. The second observer did not view the re-administration of a lesson in the event of an error. Only lesson implementation was observed for lesson procedural integrity purposes and not probe implementation. The second observer collected procedural integrity data on 23% of all lessons implemented. The observer watched the recordings of the lessons and followed along with the book to ensure that the implementer followed the scripts provided for the lesson. Integrity was measured by the number of steps accurately completed, divided by the number of steps required for that lesson, and multiplied by 100%.

The procedural integrity score reached a mean of 92% of steps among observed sessions (range, 84% to 100%). The most common error was skipping the "let's read that again" instruction in the lessons. Occasionally, the implementer also mispronounced the /th/ sound.

Social Validity

To assess social validity, the implementing first author created a questionnaire for Ryan to answer. The social validity questionnaire was given to Ryan 2 weeks after the intervention was completed. The implementer read the questions to Ryan, who responded with a spoken response. The questionnaire included the following questions: (a) "Did you like learning to read?" (b) "What did you like most about it?" (c) "What did you not like about it?" (d) "Were the lessons easy to understand?" and (e) "Would you like to do it again?" Ryan responded (a) "Yes, I like reading." (b) "Reading books." (c) "No." (d) "Yes." and (e) "Yes, I like reading." The implementer accepted Ryan's answers and finished by thanking him for answering the questions.

Results

When conducting the first whole word probe, Ryan did not read any of the 62 words and obtained a score of 0% of words read correctly. The ongoing whole word probe data are graphed in each tier of the multiple probe design to compare the subsequent unit baseline and intervention probe data and the post-intervention whole word probe data.

Unit 1 Probes

The baseline for Unit 1 words demonstrated stability after three probes with a mean score of 0%. Ryan did not correctly read the word in Unit 1. After the intervention, Ryan showed 100% improvement after reading the word in Unit 1 for three consecutive probes, and he then moved on to Unit 2.

Unit 2 Probes

Before recording baseline data for Unit 2, a whole word probe was conducted, and Ryan's score improved by 2% (one word read correctly) from the previous whole word probe. Ryan read the word taught in Unit 1 but did not read any other words. The baseline for Unit 2 consisted of Unit 2 and Unit 1 words. The baseline remained stable for the three probes and maintained at 50% of words read correctly. Ryan correctly read the word from Unit 1 but did not read the word from Unit 2. After the intervention, three probes were administered that included Unit 1 and 2 words. Ryan's score remained stable at a mean of 100% of words read correctly.

Unit 3 Probes

During the next whole word probe, Ryan scored 3% of words read correctly (two words), improving 1% from the previous whole word probe. He read all words from Units 1 and 2 correctly during the probe but did not read any words that had not been taught. Unit 3 words included all words in previously taught units. During baseline, when probing Unit 3 words, Ryan reached 50% (2 words) of words read correctly, creating a stable baseline for all three probes. After administering the intervention of Unit 3, Ryan obtained an average of 100% from the three probes. Ryan read all the words correctly and moved on to Unit 4.

Unit 4 Probes

A whole word probe was conducted, and Ryan scored 6% (four words) in words read correctly. Ryan read all words from previously taught units but did not read any words that had not been taught yet. Before administering the Unit 4 intervention, Ryan scored a mean of 33% (four words) for all three probes. He read all the words from Units 1 through 3 correctly but did not read any word from Unit 4. After completing Unit 4, Ryan scored 100% for all three probes. He read all words correctly from Units 1 through 4 and moved on to Unit 5.

Unit 5 Probes

A probe of all 62 words was conducted before taking baseline data for Unit 5 words, and Ryan scored 19% (12/62) of words read correctly. He read all words from Units 1 through 4 correctly and did not read any words that had not been taught. Ryan improved a total of 13% from the previous whole word probe. Next, Unit 5 words included all words from previous units. During baseline, Ryan scored 60% (12 words) of words read correctly for the three probes, resulting in a stable baseline. After the intervention, Ryan's score ranged from 85% to 100%. Due to a drop of words read correctly, Unit 5 was administered again. After completing Unit 5 for the second time, Unit 5 words were probed once more until the mastery criterion was met. Ryan scored 100% of words read correctly for three consecutive sessions and moved on to Unit 6.

Unit 6 Probes

A 62 whole word probe was administered, and Ryan scored 35% (22/62) in words read correctly. Two of the words Ryan read correctly had not been explicitly taught in previous units; however, the phonemes that comprised the words had been. Ryan's score increased by 16%. Next, the implementer probed all words from previous units and new words for Unit 6. Ryan's score during baseline ranged from 80% to 84% of words read correctly. Ryan correctly read all words from Units 1 through 5 and one to two words from Unit 6 that had not been taught, but the phonemes that made up the word had been taught. With a stable baseline, Ryan moved on to the intervention stage for Unit 6. After the intervention, Ryan's score ranged from 96% to 100% of correctly read words. Due to one probe being below 100%, Unit 6 was administered again, and the words were probed again. Ryan scored 100% of words read correctly for three probes and moved to Unit 7.

Unit 7 Probes

A 62 whole word probe was conducted before collecting baseline data for Unit 7. Ryan scored 44% (27/62) of words read correctly, improving his score by 9% from the previous whole word probe. Unit 7 words included all words from previous units. When probing the words for Unit 7, Ryan obtained a stable baseline of 84% (27 words) of words read correctly. He correctly read two words from Unit 7 that had not been taught yet, but the phonemes that comprised the words had been taught in previous units. After the intervention, Ryan read 100% of the words from Unit 7 and previous units. He moved on to the next unit.

Unit 8 Probes

A 62 whole word probe was conducted before collecting baseline data for Unit 8. Ryan scored 53% (33/62) of words read correctly. He showed an improvement of 9% from the previous whole word probe. Ryan read three words that had not been taught, but the phonemes that comprised the words had been taught in previous units. Ryan blended the sounds and read the words correctly within 3 seconds. Unit 8 words included untaught words from Unit 8 and all words taught from previous units. When collecting baseline data for Unit 8, Ryan read 87% (34 words) of the words. He read three words from Unit 8 that had not been taught, but the phonemes that comprised the words had been taught in previous units. After the intervention, Ryan scored 100% of words read correctly for the three probes.

Unit 9 Probes

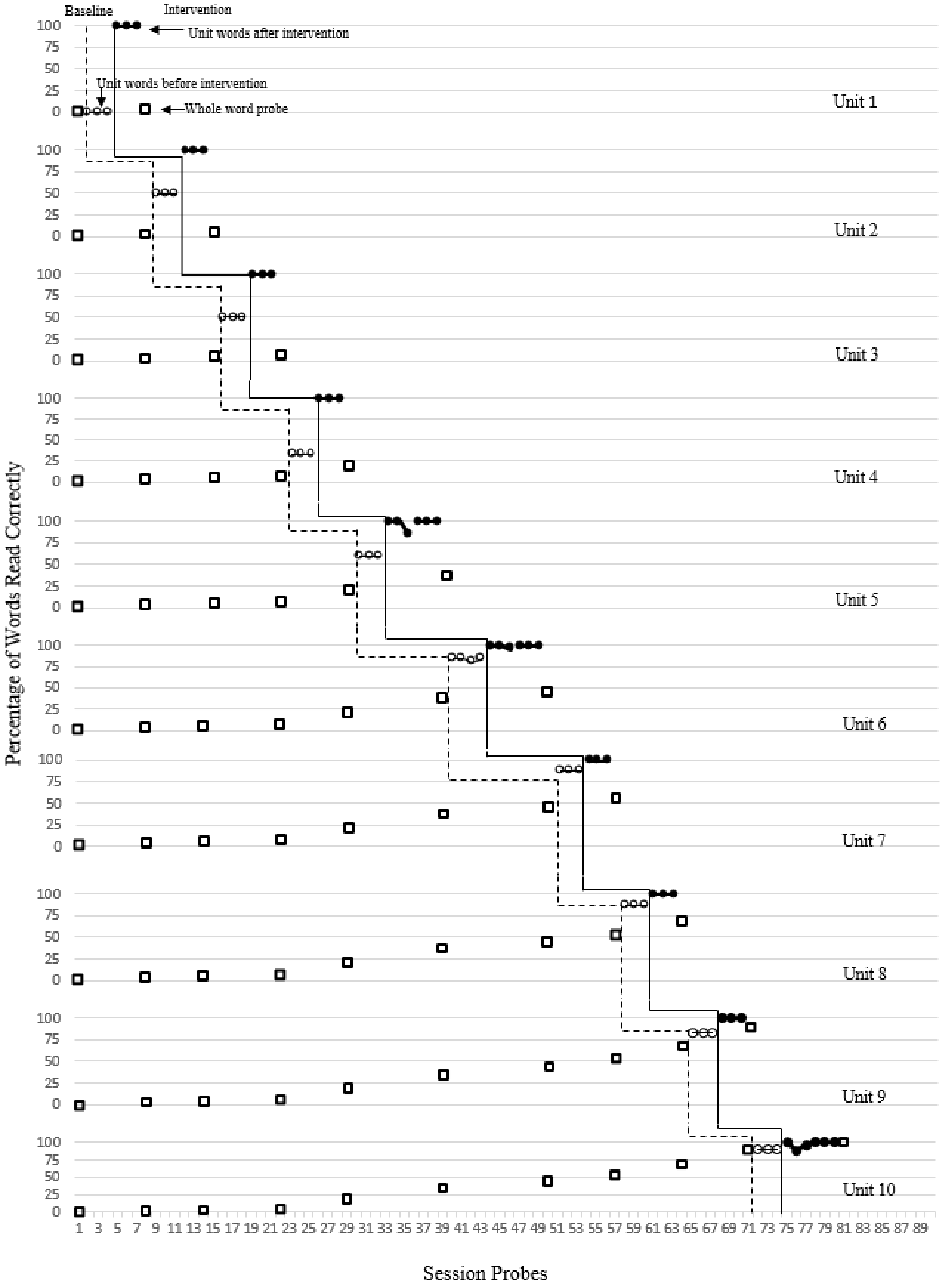
A 62 whole word probe was conducted, and Ryan scored 68% (42/62) of words read correctly. He read three words from Unit 9 that contained previously taught phonemes. Ryan's score improved by 15% from the previous whole word probe. Next, three probes were conducted with words taught in Unit 9 and previous units before Unit 9 intervention. Ryan scored an average of 84% (42 words) of words read correctly for all three probes, resulting in a stable baseline before the intervention. After the intervention, Ryan read 100% of all the words from Unit 9 for all three probes. Ryan moved on to the final unit for this study.

Unit 10 Probes

During the 62 whole word probe, Ryan scored 90% (56/62) of words read correctly. He read six out of the 12 words taught in Unit 10 that he had not been taught before, but the phonemes that comprised the words had been taught in previous units. His score improved by 22% from the previous whole word probe. Before Unit 10 intervention, all words taught in Unit 10 and previous units were probed, and Ryan scored 90% (56 words) of words read correctly in all three probes. After the intervention for Unit 10 was conducted, Ryan's score ranged from 87% to 100% of words read correctly. Ryan failed to reach 100% for all three probes, resulting in repeating Unit 10. He had trouble with the L

Figure 1

Percentage of Words Read Correctly Across Units of Instruction



sound. After administering Unit 10 again, Ryan scored 100% of words read correctly for all three probes. A final whole word probe was conducted, and Ryan's score remained at 100% of words read correctly. See Figure 1.

Discussion

The purpose of this study was to measure the effectiveness of the TYCTR approach on the acquisition of basic vocabulary words by a child diagnosed with ASD. We attempted to answer the question: When implemented with fidelity (i.e., over 80% accuracy), does TYCTR increase the acquisition of basic vocabulary words for a child diagnosed with ASD? The results demonstrated a preponderance of evidence for the TYCTR curriculum to improve the acquisition of targeted vocabulary words. Before the beginning of the study, Ryan could not read any of the 62 words targeted in the TYCTR curriculum. However, after introducing each unit, he improved in reading the words taught in each unit. He continued fluently reading the words taught in previous units (i.e., within a 3-second latency). The whole word probe results showed that Ryan read all 62 words after the end of Unit 10, fully improving from 0% before the start of the intervention. These outcomes align with similarly designed previous research studies on the TYCTR curriculum (McCollough et al., 2008; McConnell & Kubina, 2016).

An unexpected event occurred, beginning with Unit 6 and continuing through Unit 10. Ryan blended sounds and read words from units that had not been previously taught. This could be because the phonemes that made up the word had been taught in previous units. The intercept gap between unit word probes narrows from Unit 6 forward.

This study was designed to extend previous research on the TYCTR curriculum. Previous research shows that the TYCTR curriculum can be an effective strategy for teaching children to read; however, the research has been limited to populations outside of the autism spectrum (e.g., McCollough et al., 2008; McConnell & Kubina, 2016). This study increases the external validity of the TYCTR curriculum by extending it to a new population that could benefit from it.

Limitations

A limitation of the study included that only 30 lessons of the curriculum were implemented as opposed to the complete 100 lessons. This presents a barrier to fully knowing if Ryan's progress would have continued to improve in later lessons.

Next, this study's procedural integrity processes were limited because only lesson implementation sessions were included. Procedural integrity for the implementation of probe sessions was not included.

The most significant limitation of this study is the flaws in the single-case research design. The same whole word probes are represented in each concurrent baseline versus individualized data unique to the tier. The whole word probes are the only data with concurrent or stacking baseline sessions, whereas the unit word probes only occurred immediately before and after the intervention. The graphing and data collection approaches open the design to internal validity threats, such as the potential for sequence effects; as such, an increasing baseline trend in the whole word probes is observed across baseline sessions, further preventing conclusive outcomes based on the nontraditional approach to concurrent multiple probe data. Had the data been graphed to represent only the unit target words in each probe set, the evidence analysis process may have been improved. However, the unit word probes were included to show the individualized unit data immediately before and after the target units, and these data remain stable in baseline with level increases consistently from baseline to post-intervention probes. Although the data are compelling beyond case study data, an evidence analysis of a functional relation would not be appropriate.

Future Research

The current study showed that the TYCTR curriculum could help children with ASD learn to read. However, whether Ryan would have maintained or generalized progress beyond the curriculum word targets is unknown. Future research should focus on following participants throughout the full curriculum and beyond to determine long-term impacts. For example, McCollough et al. (2008) had a strong model design that measured targeted words and words derived from those target words to probe generalization using a single-case research design. Lastly, future research would benefit from focusing on expanding the knowledge about the effectiveness of TYCTR on children with ASD and other populations in an attempt to increase external validity.

Implications for Practitioners

Though the TYCTR curriculum is aimed at parent implementers, this research expands the current knowledge base, further demonstrating the range of individuals who can implement the curriculum with fidelity (McConnell & Kubina, 2016). This study also showed that children with ASD may benefit from this curriculum. Practitioners such as special education teachers and their paraprofessionals could potentially use TYCTR to implement with students with ASD who demonstrate readiness. The TYCTR curriculum includes scripted instructions with evidenced-based methods such as direct instruction and errorless teaching. The TYCTR curriculum shows excellent potential for use with different populations and settings with its easy-to-follow instructions and evidence-supported instructional methods.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Becker, W. C. (1977). Teaching reading and language to the disadvantaged—What we have learned from field research. *Harvard Educational Review, 47*(4)*,* 518-543. https://doi.org/10.17763/haer.47.4.51431w6022u51015

Carta, J. J., Greenwood, C. R., Atwater, J., Goldstein, H., Kaminski, R. A., & McConnell, S. R. (2015). Identifying preschool children for higher tiers of language and early literacy instruction within a response to intervention framework. *Journal of Early Intervention*, *36*(4), 281–291. https://doi.org/10.1177/1053815115579937

Connor, C. M., Alberto, P. A., Compton, D. L., & O'Connor, R. E. (2014). *Improving reading outcomes for students with or at risk for reading disabilities: A synthesis of the contributions from the Institute of Education Sciences Research Centers* (NCSER 2014-3000) [Grant]. National Center for Special Education Research. https://ies.ed.gov/ncser/pubs/20143000/

Denton, C. A. (2012). Response to intervention for reading difficulties in the primary grades: Some answers and lingering questions. *Journal of Learning Disabilities, 45*(3), 232–243. https://doi.org/10.1177/0022219412442155

Engelmann, S., & Bruner, E. C. (1977). *DISTAR library.* Science Research Associates.

Engelmann, S., Haddox, P., & Bruner, E. (1983). *Teach your child to read in 100 easy lessons*. Simon & Schuster.

Fjortoft, A., McLaughlin, T., Derby, M., Everson, M., & Johnson, K. (2014). The effects of two direct instruction teaching procedures to basic skills to two students with disabilities. *Multidisciplinary Journal of Educational Research*, *4*(2), 151–182. https://doi.org/10.4471/remie.2014.09

Johnson, E. S., & Boyd, L. (2013). Designing effective tier 2 reading instruction in early elementary grades with limited resources. *Intervention in School and Clinic*, *48*(4), 203–209. https://doi.org/10.1177/1053451212462881

Johnson, J., Luiten, L. M., Derby, K. M., McLaughlin, T. F., Weber, K. P., & Johnson, M. (2001). Evaluating the effectiveness of *Teach Your Child to Read in 100 Easy Lessons* using graded word lists. *Proven Practice: Prevention and Remediation Solutions for Schools, 3*(2), 68-74.

McCollough, D., Weber, K., Derby, M. K., & McLaughlin, T.F. (2008). The effects of *Teach Your Child to Read in 100 Easy Lessons* on the acquisition and generalization of reading skills with a primary student with ADHD/PI. *Child and Family Behavior Therapy, 30*(1), 61-68. https://doi.org/10.1300/J019v30n01_05

McConnell, B., & Kubina, R. (2016). Parents using explicit reading instruction with their children at-risk for reading difficulties. *Education and Treatment of Children, 39*(2), 115-139. https://doi.org/10.1353/etc.2016.0010

McLaughlin, M. R. (2011). Speech and language delay in children. *American Family Physician, 83*(10), 1183-1188.

Mueller, M. M., Palkovic, C. M., & Maynard, C. S. (2007). Errorless learning: Review and practical application for teaching children with pervasive developmental disorders. *Psychology in the Schools*, *44*(7), 691–700. https://doi.org/10.1002/pits.20258

National Reading Panel. (2000). *Teaching children to read: An evidence-based assessment of the scientific research literature on reading and its implications for reading instruction*. National Institute of Child Health and Human Development.

Rimmer, C., Dahary, H., & Quintin, E. M. (2022). Emergent literacy skills and autism: A scoping review of intervention programs. *Research in Autism Spectrum Disorders*, *97*, 1-19. https://doi.org/10.1016/j.rasd.2022.102004

Tárraga-Mínguez, R., Gómez-Marí, I., & Sanz-Cervera, P. (2020). Interventions for improving reading comprehension in children with ASD: A systematic review. *Behavioral Sciences*, *11*(3), 3-13. https://doi.org/10.3390/bs11010003

Thompson, T. (2008). *Making sense of autism.* Paul H. Brookes.

Please address correspondence to Jennifer Ninci, Department of Special Education, University of Hawaiʻi at Mānoa, 1776 University Ave, Honolulu, HI 96822, USA. Email: jninci@hawaii.edu. ORCID iD: https://orcid.org/0000-0001-6527-4297

Council for Exceptional Children

DADD

Division on Autism and Developmental Disabilities

The voice and vision of special education

Visit the official Website of the

Division on Autism and Developmental Disabilities:

https://dadd.exceptionalchildren.org