Title
Caregiver Perspectives on Service Needs for Individuals with Profound Autism

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Caregiver Perspectives on Service Needs for Individuals with Profound Autism

A dissertation submitted in partial satisfaction of the requirements for the degree

Doctor of Philosophy in Counseling, Clinical, and School Psychology

by

Emily Frances Ferguson

Committee in charge:

Professor Ty Vernon, Chair

Professor Miya Barnett

Dr. Jon Goodwin, Lecturer

September 2023

The dissertation of Emily Frances Ferguson is approved.

Miya Barnett, PhD

Jon Goodwin, PhD

Ty Vernon, PhD, Committee Chair

March 2023

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VITA OF EMILY FERGUSON
MARCH 2023

EDUCATION

2022-Present **Predoctoral Clinical Psychology Internship**
University of California, Los Angeles, CA (APA Accredited Program)
Autism and Neurodevelopmental Disabilities Track

2018-Present **Ph.D., Counseling, Clinical, and School Psychology (Clinical Emphasis)**
University of California, Santa Barbara, CA (APA Accredited Program)
Dissertation: Improving Services for Individuals with Profound Autism: A Mixed Methods Study of Caregiver Perspectives
Advisor: Ty Vernon, Ph.D.

2020 **M.A., Counseling Psychology**
University of California, Santa Barbara, CA

2015 **B.A., Psychology**
Haverford College, Haverford, PA

GRANTS, AWARDS, AND FELLOWSHIPS

2022 **Fahs-Beck Fund Doctoral Dissertation Research Grant**
Fahs-Beck Fund for Research and Experimentation ($3,167)

2021 **Ray E. Hosford Award for Excellence in Clinical Dedication**
University of California, Santa Barbara

2021 **Counseling, Clinical, and School Psychology Dissertation Fellowship**
University of California, Santa Barbara

2020 **Autism Science Foundation Pre-Doctoral Fellowship**
Awarded, but funding delayed indefinitely due to COVID-19 ($25,000)
Project Title: Innovative Approaches to Quantifying Outcomes in a Social Communication Intervention for Autistic Adults with High Support Needs

2020 **Thomas G. Haring Memorial Fellowship**
Excellence in Scholarship and Clinical Practice for Individuals with Special Needs
University of California, Santa Barbara

2019 **INSAR Student and Trainee Award**
International Society for Autism Research Annual Conference, Montreal, Canada

PUBLICATIONS

Vernon, T.W., **Ferguson, E.F.,** Jimenez-Muñoz, M., Arias, A., & Russell, K.M. (in press). Pivotal Response

Treatment at the University of California Santa Barbara. In S. Peterson & R.R. Eldridge (Eds.), *Effective programs for treating ASD: Applied behavior analysis models.* Routledge.

Ferguson, E.F., Russell, K., Licona, S., & Vernon, T. W. (submitted). Including individuals with profound autism in clinical research: A call to action and suggested practices.

Ferguson, E.F., Jimenez-Muñoz, M., Feerst, H., & Vernon, T. W. (2022). Predictors of satisfaction with autism treatment services during COVID-19. *Journal of Autism and Developmental Disorders, 52*(8), 3686-3697.

Schuck R.K., Tagavi, D.M., Baiden, K.M., Dwyer, P., Williams, Z.J., Osuna, A., **Ferguson, E.F.**, ... &Vernon, T.W. (2021). Neurodiversity and autism intervention: Reconciling perspectives through a naturalistic developmental behavioral intervention framework. *Journal of Autism and Developmental Disorders*, 1-21.

Ferguson, E.F., Drapalik, K. N., Liang, J., Hua, K., Feerst, H., Mallory, A. B., & Vernon, T. W. (2021). Social interaction skill intervention for autistic adults with intellectual disability and limited language: A pilot of the SKILL program. *Journal of Autism and Developmental Disorders*, *51*(5), 1641-1657.

Ferguson, E.F., Nahmias, A. S., Crabbe, S., Liu, T., Mandell, D. S., & Parish-Morris, J. (2020). Social language opportunities for preschoolers with autism: Insights from audio recordings in urban classrooms. *Autism*, *24*(5), 1232-1245.

Parish-Morris, J., Pallathra, A. A., **Ferguson, E.,** Maddox, B. B., Pomykacz, A., Perez, L. S., ... & Brodkin, E. S. (2019). Adaptation to different communicative contexts: an eye tracking study of autistic adults. *Journal of neurodevelopmental disorders*, *11*(1), 5.

Parish-Morris, J., Sariyanidi, E., Zampella, C., Bartley, G. K., **Ferguson, E.,** Pallathra, A. A., ... & Tunç, B. (2018). Oral-Motor and lexical diversity during naturalistic conversations in adults with autism spectrum disorder. In *Proceedings of the conference. Association for Computational Linguistics. North American Chapter. Meeting* (Vol. 2018, p. 147). NIH Public Access.

Parish-Morris, J., Liberman, M. Y., Cieri, C., Herrington, J. D., Yerys, B. E., Bateman, L., Donaher., J., **Ferguson, E.,** Pandey. J., & Schultz, R. T. (2017). Linguistic camouflage in girls with autism spectrum disorder. *Molecular Autism*, *8*(1), 1-12.

Parish-Morris, J., Liberman, M., Ryant, N., Cieri, C., Bateman, L., **Ferguson, E.,** & Schultz, R. T. (2016, June). Exploring autism spectrum disorders using HLT. In *Proceedings of the conference. Association for Computational Linguistics. Meeting* (Vol. 2016, p. 74). NIH Public Access.

Parish-Morris, J., Cieri, C., Liberman, M., Bateman, L., **Ferguson, E.,** & Schultz, R. T. (2016). Building language resources for exploring autism spectrum disorders. In *International Conference on Language Resources and Evaluation* (Vol. 2016, p. 2100). NIH Public Access.

PRESENTATIONS

Ferguson, E.F., Arias, A., Licona, S., Jimenez-Muñoz, M., Russell, K., Adams, P., Nees, A., Vernon, T.W.

(2022). *Pivotal for early autism intervention: Preliminary outcomes of a smartphone app-based parent education program* [Panel Presentation]. International Society for Autism Research, Austin, Texas, USA.

Ferguson, E.F., Jimenez-Muñoz, M., Feerst, H., Vernon, T.W. (2021). P*sychological wellbeing and service satisfaction during COVID-19 and beyond* [Poster Presentation]. International Society for Autism Research, Virtual Conference.

Jimenez-Muñoz, M., **Ferguson, E.F.,** Feerst, H., Vernon, T.W. (2021). *Predictors of service priorities during COVID-19 and beyond* [Poster Presentation]. International Society for Autism Research, Virtual Conference.

Ferguson, E.F, Hua, K., Liang, J., Feerst, H., Drapalik, K., Mallory, A., Sanford-Rodriguez., J., Nawrocki, H., Vernon, T.W. (2020). *A targeted social communication group intervention for adults on the autism spectrum with limited functional language.* International Society for Autism Research, Seattle, Washington. (Conference Cancelled.)

Zampella, C.J., Cordero, L., **Ferguson, E.F.,** Cola, M., Petrulla, V., Riiff, A., Pandey, J., Schultz, R.T., Parish-Morris, J., & Herrington, J.D. (2020). *Towards a fully automated computer vision approach for measuring facial affect in ASD.* International Society for Autism Research, Seattle, Washington. (Conference Cancelled.)

Tagavi, D., Bordofsky, A., Chau, S., **Ferguson, E.F.,** Vernon, T.W. (2020). *Changes in psychophysiological arousal in toddlers with ASD and TD toddlers following exposure to parent social activities.* International Society for Autism Research, Seattle, Washington. (Conference Cancelled.)

Ferguson, E.F., Ko, J., McGarry, E., Cohen, S., Miller, A., Vernon, T.W. (2019). *Empathy and emotion regulation in an adult social skills intervention* [Poster Presentation]. International Society for Autism Research, Montreal, Canada.

Ferguson, E.F., Liu, T., Nahmias, A., Crabbe, S., Schultz, R.T., Mandell, D., & Parish-Morris, J. (2018, July). *Inclusion for preschoolers with autism: New insights using LENA in urban classrooms* [Poster Presentation]. International Congress of Infant Studies, Philadelphia, Pennsylvania, USA.

Ferguson, E.F., Bateman, L., Cola, M. L., Dravis, Z. M., Uh, S., Plate, S., Minyanou, N., Pomykacz, A., Bassanello, K., Zoltowski, A., Herrington, J., Bartley, K., Kim, E. S., de Marchena, A., Pandey, J., Schultz, R. T., Parish-Morris, J. (2018, May). *Individuals with and without ASD describe "Funny" videos in similar ways* [Poster Presentation]. International Society for Autism Research, Rotterdam, Netherlands.

Bateman, L., **Ferguson, E.F.,** Cola, M. L., Uh, S., Plate, S., Dravis, Z. M., Pomykacz, A., Bassanello, K., Zoltowski, A., Herrington, J., Bartley, K., Kim, E. S., de Marchena, A., Pandey, J., Schultz, R. T., Parish-Morris, J. (2018). *"Thin-Slicing" everyday conversations: A quick, low-cost way to add new dimensionality to ASD conceptualization* [Poster Presentation]. International Society for Autism Research, Rotterdam, Netherlands.

Boorse, J., Bateman, L., **Ferguson, E.F.,** Cola, M. L., Uh, S., Plate, S., Dravis, Z. M., Pomykacz, A., Bassanello, K., Zoltowski, A., Herrington, J., Bartley, K., Kim, E. S., de Marchena, A., Pandey, J., Schultz, R. T., Parish-Morris, J. (2018). *Cognitive orientation and linguistic diversity in the narratives and retellings of children with ASD vs. controls* [Poster Presentation]. International Society for Autism Research, Rotterdam, Netherlands.

Cola, M. L., **Ferguson, E.F.,** Bateman, L., Uh, S., Plate, S., Dravis, Z. M., Pomykacz, A., Bassanello, K., Zoltowski, A., Herrington, J., Bartley, K., Kim, E. S., de Marchena, A., Pandey, J., Schultz, R. T., Parish-Morris, J. (2018). *A mixed models approach to analyzing large cohorts of natural conversational data from individuals with ASD* [Poster Presentation]. International Society for Autism Research, Rotterdam, Netherlands.

Uh, S., Bateman, L., **Ferguson, E.F.,** Cola, M. L., Plate, S., Dravis, Z. M., Pomykacz, A., Bassanello, K., Zoltowski, A., Herrington, J., Bartley, K., Kim, E. S., de Marchena, A., Pandey, J., Schultz, R. T., Parish-Morris, J. (2018). *Indexing social focus in the natural conversations of individuals with and without ASD* [Poster Presentation]. International Society for Autism Research, Rotterdam, Netherlands.

Parish-Morris, J., Pallathra, A. A., **Ferguson, E.F.,** Bateman, L., Cola M. L., Uh, S., Dravis, Z. M., Zoltowski, A., Pomykacz, A., Bassanello, K., Day-Watkins, J., Maddox, B. B., Miller, J., Dichter, G. S., Connell, J., Mandell, D. S., Schultz, R. T. (2018). *The effect of TUNE-in treatment on naturalistic conversation in adults with ASD: Speaking rate is a temporal marker of rapport* [Poster Presentation]. International Society for Autism Research, Rotterdam, Netherlands.

Ferguson, E.F., Brown, J., Bateman, L., Dravis, Z.M., Cola, M., Pomykacz, A., de Marchena, A.B., Bartley, K., Kim, E.S., Pandey, J., Schultz, R.T., Parish-Morris, J. (2017, June). *Humor responses and social referencing in children with ASD: The role of social cognitive complexity* [Poster Presentation]. Leadership Education in Neurodevelopmental Disabilities (LEND) Leadership and Poster Day, Children's Hospital of Philadelphia, Philadelphia, PA, USA.

Ferguson, E.F., Brown, J., Bateman, L., Dravis, Z.M., Cola, M., Pomykacz, A., de Marchena, A.B., Bartley,K., Kim, E.S., Pandey, J., Schultz, R.T., Parish-Morris, J. (2017, May). *Humor responses and social referencing in children with ASD: The role of social cognitive complexity* [Poster Presentation]. International Meeting for Autism Research, San Francisco, CA, USA.

Liu, T., Regan, S., **Ferguson, E.F.**, Bateman, L., Nahmias, A., Mandell, D., Schultz, R.T., Parish-Morris, J. (2017, May). *Real-world conversational turn-taking: An exploratory study of preschoolers with ASD, teachers, and peers* [Poster Presentation]. International Meeting for Autism Research, San Francisco, CA, USA.

Santulli, M., Parish-Morris, J., **Ferguson, E.F.**, Bateman, L., Schultz, R.T., Donaher, J.G. (2016, November). *Deciphering disfluencies in ASD* [Poster Presentation]. American Speech-Language Hearing Association. Philadelphia, PA, USA.

Ferguson, E.F., Nahmias, A., Bateman, L., Payton, K.J., Mandell, D., Schultz, R.T., Parish-Morris, J. (2016, May). *Peer versus teacher talk in early intervention classrooms: Case studies suggest that inclusion might be different* [Poster Presentation]. International Meeting for Autism Research, Baltimore, MD, USA.

Bateman, L., **Ferguson, E.F.**, Payton, K.J., Schultz, R.T., Parish-Morris, J. (2016, May). *Family matters: Children and adolescents with ASD talk more about family than friends* [Poster Presentation]. International Meeting for Autism Research, Baltimore, MD, USA.

Rudoler, J., **Ferguson, E.F.**, Bateman, L., Lin, K., Regan, S., Paul, N., Cai, T., Schultz, R.T., Parish-Morris, J. (2016, February). *Early intervention for preschoolers with autism spectrum disorder: Developing a* *reliable segmentation protocol for classroom audio recordings* [Poster Presentation]. Children's Hospital of Philadelphia Research Poster Day, Philadelphia, PA, USA.

RESEARCH EXPERIENCE

2020-Present **Dissertation Research**
Title: Improving Services for Individuals with Profound Autism: A Mixed Methods Study of Caregiver Perspectives
Committee: Ty Vernon, Ph.D. (Chair), Miya Barnett, Ph.D., Jon Goodwin, Ph.D.

- Employ quantitative and qualitative methods to gather stakeholder perspectives on the service landscape for individuals with profound autism across the U.S.
- Identify barriers and facilitators of treatment access and priority treatment targets for this underserved population

2020-2022 **Project Coordinator**
AR190105, Department of Defense CDMRP (Clinical Translational Research Award)
Title: Clinicianless Training in Autism Treatment: An Adaptive Online Parent Education Program
University of California, Santa Barbara
Principal Investigators: Ty Vernon, Ph.D. and Andrew Maul, Ph.D.

- Coordinate RCT to develop a self-directed, interactive smartphone application to train parents of young children in Pivotal Response Treatment
- Create standard operating procedures; develop Redcap database for project; oversee development of the *Pivotal* app; prepare behavioral coding procedures

2018-2020 **Master's Thesis Research Project**
University of California, Santa Barbara, Academic Senate Funding
Title: Social Interaction Intervention for Autistic Adults with Intellectual Disability and Limited Language: A Pilot of the SKILL Program

- Developed and implemented a group socialization program (SKILL) for adults with profound autism
- Assessed preliminary feasibility, acceptability, and efficacy of SKILL program for targeting social interaction skills in this under-resourced population

2019-2020 **Co-Investigator/ Graduate Student Researcher**
Cottage Hospital Research Institute Research Grant
Title: Parent-Child Bio-Behavioral Synchrony in Autism
University of California, Santa Barbara
Principal Investigator: Ty Vernon, Ph.D.

- Provided weekly Parent Education sessions in Pivotal Response Treatment for toddlers on the autism spectrum; monitored implementation fidelity
- Utilized biosensors to obtain biobehavioral data from parent-child dyads engaged in play interactions

2018-2019 **Co-Investigator/Graduate Student Researcher**
Title: Rewarding Engagement and Adaptive Communication in Children (REACCH): An Infant-Toddler Playgroup to Support Early Social Development
University of California, Santa Barbara

- Co-facilitated a parent-child playgroup to promote social engagement in infants and toddlers at-risk for ASD

- Contributed to development of a group curriculum to train parents in motivating intervention strategies to promote gestures, eye contact, positive facial expressions, and vocalizations

2015-2018 **Clinical Research Assistant**
*Center for Autism Research**,** The Children's Hospital of Philadelphia, Philadelphia, PA*
Supervisors: Robert Schultz, Ph.D. and Julia Parish-Morris, Ph.D.

- Coordinated a large-scale study to characterize facial expressions, language, and social synchrony in individuals with and without autism spectrum disorder
- Collected natural language and facial data during study visits; managed transcription of ADOS recordings and other conversation-based paradigms

2015-2016 **Clinical Research Assistant**
Center for Mental Health Policy and Services, University of Pennsylvania, Philadelphia, PA
Supervisors: David Mandell, ScD and Julia Parish-Morris, PhD

- Collected audio-recordings from children on the autism spectrum to characterize individual language profiles and early intervention environments
- Achieved reliability on a structured classroom observation and coded relevant behaviors

CLINICAL EXPERIENCE

2022-Present **Clinical Psychology Intern**
UCLA Child and Adult Neurodevelopmental (CAN) Clinic, Los Angeles, CA
Supervisors: Patricia Renno, PhD, Amanda Gulsrud, PhD, Elizabeth Laugeson, PhD

- Conduct cognitive behavioral therapy for anxiety and depression in autistic youth
- Lead PCIT sessions for youth with autism and intellectual disability
- Implement social facilitation strategies with autistic children and adolescents
- Facilitate group social skills interventions through the PEERS program
- Conduct treatment consultation sessions for parents and families

Current Elective Rotation: UCLA Child OCD, Anxiety & Tic Disorders Clinic

- Learn evidenced-based therapies for treating OCD and Tic Disorders in youth with and without neurodevelopmental disabilities
- Lead individual therapy sessions for clients with complex diagnostic profiles

2018-2022 **Senior Clinician**
Treatment Clinic, Koegel Autism Center, Santa Barbara, CA
Supervisors: Ty Vernon, Ph.D. and Anna Krasno, Ph.D.

- Conducted individual therapy and used social facilitation strategies with children, adolescents, and adults on the autism spectrum
- Provided parent education in empirically validated interventions, including Pivotal Response Treatment, functional assessment, self-management, priming, and social communication training

2019-2022 **Licensed PCIT International Clinician**
Parent-Child Interaction Therapy (PCIT) Clinic, Santa Barbara, CA
Supervisor: Miya Barnett, Ph.D.

- Provided weekly behavioral therapy for families with children aged 2-7 years with challenging behaviors; coded and monitored progress to track skill acquisition

- Coached caregivers in strategies to enhance their relationship with their child, increase positive behaviors, and reduce problem behaviors
- Provided time-limited, intensive PCIT for ASD as part of a research study

2020-2021 **Registered Psychological Assistant**
Child Abuse Listening Mediation (CALM), Santa Barbara, CA
Supervisor: Rachel Hopsicker, Ph.D.

- Provided outpatient individual/ family therapy and parent training for children aged 2-15 years old who have experienced or are at-risk for trauma
- Conducted comprehensive assessments; developed culturally-sensitive treatment plans; established goals and objectives aligned with trauma-informed treatment modalities such as TF-CBT

2020-2022 **Senior Clinician and Program Supervisor**
Personal Vocational Rehabilitation Services, Department of Rehabilitation (DOR)
Koegel Autism Center, Santa Barbara, CA
Supervisor: Anna Krasno, Ph.D.

- Provided training to autistic adults to facilitate employment outcomes
- Facilitated program and intakes; coordinated with undergraduate peer mentors, parents, and directors to streamline services

2019-2020 **Advanced Practicum Clinician**
Hosford Counseling & Psychological Services Clinic, Santa Barbara, CA
Supervisors: Maryam Kia-Keating, Ph.D. and Heidi Zetzer, Ph.D.

- Provided weekly outpatient therapy sessions to adolescents and adults diagnosed with depressive disorders, anxiety disorders, personality disorders
- Conducted clinical intakes and presented case conceptualizations
- Received advanced training in empirically-based therapies, cultural/ethnic diversity considerations, and diverse theoretical orientations

2018-2019 **Practicum Clinician**
Hosford Counseling & Psychological Services Clinic, Santa Barbara, CA
Supervisor: Heidi Zetzer, Ph.D.

- Provided time-limited outpatient therapy sessions to adolescents and adults
- Conducted clinical intakes and presented case conceptualizations

ASSESSMENT EXPERIENCE

2022-Present **Assessment Clinician**
Assessment Clinic, UCLA Child and Adult Neurodevelopmental Clinic, Los Angeles, CA
Supervisors: Patricia Renno, PhD, Amanda Gulsrud, PhD, Catherine Lord, PhD

- Administer comprehensive neurodevelopmental assessments across the lifespan
- Present testing results to multi-disciplinary treatment team to develop rich case conceptualizations
- Write comprehensive psychological reports and conduct oral feedback sessions
- Train to reliability on standardized measures, including ADOS-2 and ADI-R
- Collaborate with interpreters as needed to translate assessments

2019-2022 **Senior Assessment Clinician**
Assessment Clinic, Koegel Autism Center, Santa Barbara, CA

Supervisors: Ty Vernon, Ph.D. and Anna Krasno, Ph.D.

- Administered neuropsychological assessment batteries across the lifespan
- Synthesized test results with interviews to develop rich case conceptualizations
- Wrote comprehensive psychological reports and conducted oral feedback sessions
- Experience with ADOS-2 (all modules), ADI-R, Mullen Scales of Early Learning, DAS-II Early Years and School Aged Battery, WAIS-IV, WISC-V, TONI-4, NEPSY-II, PLS-5, EVT-3, PPVT-5, CELF-5, Vineland-III, BASC-3, BRIEF-2, Connors-3, Beck Scales, TAT, RAT-II.

2020-2022 **Assessment Clinician**
Mind and Behavior Assessment Clinic, Santa Barbara, CA
Supervisor: Miriam Thompson, Ph.D.

- Administered neuropsychological assessment batteries to children and caregivers, including clinical interviews, WJ-IV-ACH, WJ-IV-COGS, WMS-IV, etc.
- Integrated psychological and neuropsychological assessment results
- Participated in weekly assessment didactics synthesizing results from interviews, medical records, developmental history, cognitive, social-communication, and other symptoms measures

SUPERVISORY EXPERIENCE

2018-2022 **Clinical Supervisor**
Koegel Autism Center, Santa Barbara, CA
Supervisors: Ty Vernon, Ph.D. and Anna Krasno, Ph.D.

- Provided training to new graduate clinicians in psychological assessment and feedback procedures
- Provided weekly supervision to undergraduate behavior therapists providing services to children and adults
- Conducted trainings in the motivational and behavioral principles of Pivotal Response Treatment and ensured clinicians were meeting intervention fidelity
- Coordinated with Autism Center directors to ensure quality of care

INVITED PRESENTATIONS AND WORKSHOPS

Fall 2021 **Community Training Presenter & Workshop Facilitator**
Autism Training, Student Health Services, University of California, Santa Barbara, CA

- Presentation title: “Neurodiversity and Considerations for Autistic College Students”

Winter 2019 **Community Training Presenter & Workshop Facilitator**
Autism Seminar, Santa Barbara Public Library, Santa Barbara, CA

- Presentation title: “Promoting Flexibility One Day at a Time”

Summer 2019 **Community Training Presenter & Workshop Facilitator**
Santa Barbara Neighborhood Clinic, Santa Barbara, CA

- Presentation title: “Diagnosing and Treating Autism Spectrum Disorder”

Spring 2019 **Community Training Presenter & Workshop Facilitator**

Santa Barbara Public Library, Santa Barbara, CA

- Presentation title: “Keeping Your Cool: Coping Skills for Children, Parents, and Teens”

MEMBERSHIP AND REVIEWING

2019 – Present	**Autism Journal,** *Ad Hoc Reviewer*
2019 – Present	**National Council of Severe Autism,** *Affiliate*
2018 – Present	**Journal of Autism and Developmental Disorders,** *Ad Hoc Reviewer*
2016 – Present	**International Society for Autism Research**, *Student Affiliate*

TEACHING EXPERIENCE

Spring 2022 **Course Teaching Assistant**
Introduction to Helping Skills (CNCSP 101: Undergraduate Course)
University of California, Santa Barbara, Professor: Arlene Ortiz, Ph.D.

Fall 2020 **Guest Lecturer**
Introduction to Autism (ED 190: Undergraduate Course)
University of California, Santa Barbara, Professor: Ty W. Vernon, Ph.D.
Lecture title: “Diagnosing and Treating Children and Adults with Autism and Intellectual Disability”

Fall 2020 **Course Teaching Assistant**
Introduction to Autism (ED 190: Undergraduate Course)
University of California, Santa Barbara, Professor: Ty W. Vernon, Ph.D.

Spring 2020 **Course Teaching Assistant**
Psychology of Gender (CNSCP 114: Undergraduate Course)
University of California, Santa Barbara, Professor: Tania Israel, Ph.D.

Fall 2019 **Guest Lecturer**
Introduction to Autism (ED 190: Undergraduate Course)
University of California, Santa Barbara, Professor: Ty W. Vernon, Ph.D.
Lecture title: “Interventions for School-Aged Children with Autism”

Fall 2019 **Course Teaching Assistant**
Introduction to Autism (ED 190: Undergraduate Course)
University of California, Santa Barbara, Professor: Ty W. Vernon, Ph.D.

Summer 2019 **Course Teaching Assistant**
College Student Peer Helping and Leadership (CNCSP 115: Undergraduate Course)
University of California, Santa Barbara, Professor: Steve Smith, Ph.D.

ABSTRACT

Caregiver Perspectives on Service Needs for Individuals with Profound Autism

by

Emily Frances Ferguson

Profound autism describes individuals on the autism spectrum who have co-occurring intellectual disability or minimal verbal ability and require continuous access to care. The notable underrepresentation of individuals with profound autism in the research literature has resulted in limited knowledge about their service needs and a lack of evidence-based practices tailored to these needs. This mixed-methods study sought caregiver perspectives on service needs, barriers to service access, and treatment priorities to guide future treatment development and improvement of service delivery. Quantitative findings indicated that regular socialization opportunities were the most frequently endorsed unmet service need, followed by access to primary health care services by autism-trained medical staff, social skills instruction, life skills instruction, occupational therapy, and behavioral support. Lower socioeconomic status was associated with a greater number of unmet service needs. Increased age and greater feelings of sadness were associated with higher likelihoods of needing social skills instruction, life skills instruction, and occupational therapy. Elevated emotional reactivity and higher language level were associated with greater needs for social clubs and activity groups. Thematic analysis of qualitative data revealed a pervasive shortage of individualized services to promote ongoing skill development and socialization opportunities for adolescents and adults with profound autism. Perspectives on treatment priorities indicated a need for integrated service settings with multiple trained providers, evidence-based practices for challenging behaviors and low adaptive functioning, respite care, and service navigation support. Ultimately, this integration of qualitative and quantitative findings provides new insights into service needs for adolescents and adults with profound autism to improve the accessibility and quality of clinical care.

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Chapter One:

Caregiver Perspectives on Service Needs for Individuals with Profound Autism

The notable underrepresentation of individuals with profound autism[1] in the research literature has resulted in a lack of evidence-based practices (EBPs) and knowledge about their service needs (Siegel, 2018; Stedman et al., 2019). This underrepresentation is particularly striking given documented increases in the prevalence of autism and co-occurring intellectual disability (ID) over the past few years (Christensen et al., 2018). ID is defined by deficits in intellectual and adaptive functioning that reduce independent functioning across social, conceptual, and practical domains (DSM-5-TR, 2022). The co-occurrence of both diagnoses may exacerbate challenges across a range of behaviors and skills and present unique treatment needs (Bertelli, 2019). Thus far, there is a lack of research that appropriately classifies language, cognitive, and behavioral functioning amongst subsets of individuals on the autism spectrum to determine service needs and the efficacy of existing services (Lord et al., 2021; Stedman et al., 2019; Thurm et al., 2022). A commission of researchers and stakeholders introduced profound autism as an administrative designation to highlight the unique and urgent needs of individuals aged eight and older on the autism spectrum who are minimally verbal or non-verbal, unable to advocate for themselves, and require 24-hour access to care. Recent estimates indicate that 18 - 48% of individuals diagnosed with autism spectrum disorder (ASD) meet the criteria for this designation (Lord et al., 2021; Singer et al., 2022) .

Knowledge is limited about the characteristics and outcomes of this population because participants with ID have only been included in approximately 6% of studies published in autism

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[1] This paper uses the term "profound autism" to distinguish individuals on the autism spectrum who have high support needs. Given the varied terminology preferred by people diagnosed with autism and their families, this paper will use "person on the autism spectrum" or identity-first language ("autistic") when not referring to profound autism specifically, as these have been shown to be the least polarizing overall (Botha et al., 2021).

journals (Russell et al., 2019). This suggests that participants with ID are often excluded or routinely under-recruited in studies that feature people on the autism spectrum (Siegel, 2018). The lack of EBPs to support the needs of adolescents and adults with profound autism (Walton & Ingersoll, 2013) may be associated with emotional and behavioral challenges over time (Duncan et al., 1999; Matson & Shoemaker, 2009; Taylor et al., 2015), poorer life outcomes (Howlin & Moss, 2012; Mason et al., 2021), and lower subjective wellbeing (Scheeren et al., 2021).

Services for Adolescents and Adults on the Autism Spectrum

The transition from adolescence into adulthood is a critical period of service and role adjustments for individuals on the autism spectrum. As autistic individuals enter adolescence, the evidence base regarding services becomes small and variable, and few studies explore the improvement of services into adulthood (Reichow & Barton, 2014; Shattuck et al., 2018; Shattuck et al., 2020). A recent review identified that a significant minority (less of 1%) of peer-reviewed studies on autism focused specifically on support systems, services, or intervention programs for adults (Shattuck et al., 2020). Evidence suggests that services begin to decline during high school and that individuals with profound autism may experience a particularly sharp decline in services after graduation (Laxman et al., 2019). These challenges accessing services may be exacerbated for individuals who demonstrate externalizing behaviors (Anderson & Butt, 2018). Thus, the lack of services into adulthood may particularly affect individuals with profound autism who require 24-hour access to care for monitoring, support, and meaningful engagement.

Although limited, past research provides some intervention strategies and treatment targets that may promote meaningful skill development in individuals with profound autism. Intervention programs have fostered social communication gains, workplace inclusion, reductions in challenging behaviors, and improved adaptive functioning for adolescents and adults with profound autism (Carminati et al., 2007; Ferguson et al., 2021; Ingersoll et al., 2017; Ryan et al., 2019; Walsh et al., 2019). The critical next step is to gather stakeholder perspectives on priority treatment targets and unmet service needs to inform and facilitate this line of research. Parents and caregivers may provide ‘experiential expertise’ regarding the most valuable types of services for individuals with profound autism throughout adolescence and adulthood (Collins & Evans, 2002; Fletcher-Watson et al., 2019).

Stakeholder Perspectives on Service Needs and Priorities

A needs assessment that examines usual care delivery patterns is an important first step to understanding and addressing barriers to optimal treatment for adolescents and adults with profound autism (Maddox et al., 2018; Powell et al., 2017). A needs assessment for this population can provide a useful benchmark to measure future efforts to increase access to appropriate care (Maddox et al., 2018). Simultaneously, gathering autism treatment priorities from key stakeholders offers valuable insight and guidance toward the selection of treatment components and objectives (Fletcher-Watson et al., 2019; Gotham et al., 2015; Nicolaidis et al., 2011; Pellicano et al., 2014). Thus far, the voices of stakeholders aligned with individuals with profound autism have not been explicitly identified in these efforts (Roche et al., 2021). In the long term, including consumers as partners in developing interventions increases the probability that these interventions will be implemented successfully in the community (Dingfelder & Mandell, 2011).

Self-reporting autistic adults and caregivers have expressed preferences for research related to immediate needs, life skills, and public services (Gotham et al., 2015; Pellicano et al., 2014; Roche et al., 2021). Sosnowy et al. (2018) interviewed parents and autistic young adults, including some adults with ASD + ID who were their own legal guardians, and they consistently reported that support services were inadequate in the transition into adulthood, given the significant decline in services after high school (Anderson et al., 2018; Cheak-Zamora & Teti, 2015; Howlin, 2021). Both parents and young adults emphasized that services needed to be flexible to meet individual needs, and more comprehensive, continuous, and integrated in order to be most useful (Sosnowy et al., 2018). It remains to be determined whether explorations focused expressly on the perspectives of families of individuals with profound autism would yield similar conclusions.

Factors Related to Unmet Service Needs

Explorations of individual and community-level factors related to unmet service needs provide a nuanced perspective on stakeholder interactions with care delivery systems. Older age (Gotham et al., 2015; Turcotte et al., 2016), more limited adaptive functioning or daily living skills (Maenner et al., 2013), minority race/ethnicity status (Baio et al., 2018), greater communication needs (Burke & Heller, 2017), and lower income (Burke & Heller, 2017; Schott et al., 2021) have been associated with lower levels of service access or utilization. The limited type and frequency of intervention services available, especially in rural areas, may negatively impact caregiver-reported satisfaction with autism services (Crais et al., 2020). Families have varied treatment priorities depending on life stage; autistic individuals over 21 years are more likely to report a need for case management services than younger individuals due to a loss of school-based supports (Schott et al., 2021). Furthermore, the presence of ID, increased ASD symptom severity, internalizing problems, and externalizing behaviors may relate to a lack of appropriate services (Vogan et al., 2014).

For individuals with profound autism, the severity of internalizing problems and externalizing behaviors seem to relate to identified service needs. Individuals with lower adaptive behavior levels (such as those implicated in ID) may display more significant challenges with emotional regulation and recovery from frustration tasks than individuals with higher adaptive behavior levels (Northrup et al., 2020). Communication level also plays a role, as individuals who are non-verbal or use single-word speech are more emotionally reactive than individuals with phrase speech and fluent speech (Northrup et al., 2020). Thus, adaptive behavior levels (Stedman et al., 2019), severity of challenges with emotion regulation, and language level (non-speaking, single words, verbally fluent) are clinical characteristics that may relate to service needs for individuals with profound autism and their families.

Current Study

The purpose of this mixed-methods study is to explore clinical service needs and treatment priorities for adolescents and adults with profound autism, as reported by their parents and caregivers. Prior mixed-methods explorations of caregiver perspectives on autism services have provided valuable information to shape the tailoring of service delivery (Brookman-Frazee et al., 2012), and similar insights may be gained from focusing on those with profound autism. The findings from this needs assessment will identify both proximal and distal objectives to facilitate the development of evidence-based services that improve family experience and outcomes (Palinkas, 2014; Powell et al., 2017). For the purposes of clinical characterization, this study focuses on three domains of functioning that may relate to treatment needs: language level, adaptive functioning, and emotional regulation. The aims of the study are to:

1. Identify caregiver-reported unmet service needs (e.g., social skills training), barriers to service access (e.g., no service providers in area), and treatment priorities (e.g., decreasing aggressive behaviors, ideal service) through quantitative and qualitative reports.
2. Explore quantitative demographic (age, race, ethnicity, SES) and clinical (language level, emotion regulation, adaptive functioning) variables as predictors of overall unmet service needs, and by service category.
3. Conduct thematic analysis of caregiver narratives to identify salient themes regarding service needs and priorities for adolescents and adults with profound autism; integrate findings with quantitative data to provide a comprehensive picture of experiences with care delivery systems and priorities for the future.

Chapter Two: Review of the Literature

The tremendous heterogeneity of the autism spectrum necessitates inclusion of individuals with diverse clinical profiles in the research literature to understand the continuum of experiences, service needs, and response to interventions. However, individuals with significant limitations in one or more domains of functioning are under-represented in autism research (Siegel, 2018). As one example, Russell et al.'s (2019) meta-analysis of 301 studies published in autism-specific journals estimated that 94% of the participants did not have concurrent ID. It is rare to find an autism research study that provides thorough individual characterization by reporting on *both* cognitive functioning and communication ability (Stedman et al., 2019). Selection biases and insufficient participant characterization limit our ability to generalize treatments outcomes to individuals with profound autism (Stedman et al., 2019; Thurm et al., 2022). Thus, providers serving individuals with profound autism often do not have access to evidence-based intervention strategies to addresses the unique needs of this population. To address these service gaps, it is important to characterize the presentations of individuals with profound autism in relation to their identified service needs.

Clinical Presentations of Profound Autism

Children and adults with severe and profound ID have vastly different educational and long-term care needs than their autistic counterparts without cognitive delays. While accurate early identification of ID may serve as a gateway to individually-tailored supports, it is difficult to verify the degree of developmental delay in young children given challenges with obtaining valid cognitive testing results, the significant developmental growth potential, and the observed gains in cognitive scores following early intervention efforts (e.g., Landa, 2018). As a result, these children may retain the same administrative designation of “autism” (without indication of cognitive delays) as children who develop fluent speech and function more independently (Lord et al., 2021). Profound autism was introduced as an administrative designation to highlight the needs of individuals on the autism spectrum who have moderate to severe intellectual disability (e.g., an intelligence quotient below 50) and/or very limited language (e.g., non-speaking or use of single words only). Profound autism is often associated with, but does not require, the presence of co-occurring self-injury, aggression, or epilepsy. This term is considered most acceptable and useful as a characterization descriptor among families of children eight years or older because cognitive and language characteristics are less likely to change in older childhood or adolescence (Lord et al., 2021). Parent advocates have endorsed profound autism as an important label to differentiate the needs of this subset of the autism spectrum and to shape research and funding priorities (Singer et al., 2022).

Autism and Intellectual Disability. Before the conceptualization of autism broadened into a spectrum disorder, most children and adults diagnosed with autism were also diagnosed with intellectual disabilities. Currently, ID or disorders of intellectual development affects approximately 30-40% of individuals diagnosed with ASD (ICD-11, 2018; Maenner et al., 2020). It is characterized by delays in cognitive abilities that lead to difficulty reaching objectives, achieving developmental or academic milestones, and learning at a practical and adaptive level. Similar to ASD, ID onsets in the first few years of life and persists across the lifespan (Bertelli, 2019). Early indications that a child may receive a later classification of ID are evident in early developmental assessments and response to early intervention (Vivanti et al., 2019). Children on the autism spectrum who demonstrate low mental age (below 12 months) at 24 months old show the least amount of developmental progress and highest symptom severity at 4 years old compared to autistic children without a low mental age, with trends suggesting that these delays persist into adulthood (Hinnebusch et al., 2017). Recent surveillance data indicates that the rates of ID co-morbidity are higher in Black youth on the autism spectrum (44%) than non-Hispanic White youth (22%; Baio et al., 2018), highlighting the need to advance research to evaluate factors contributing to these disparities (Constantino et al., 2020).

Individuals with ID have variable developmental profiles throughout the lifespan. The combination of ASD + ID presents unique challenges across a range of behaviors and skills (Boucher et al., 2008). Severe ID has been associated with a higher severity of ASD and problem behaviors (Murphy et al., 2009). Higher rates of inattention, hyperactivity, and impulsive behaviors have also been observed in adolescents with ASD + ID in comparison to those without ASD (Bradley & Isaacs, 2006). Relative to those with ASD-only, adolescents with ASD + ID tend to utilize fewer outpatient healthcare services (Nathenson & Zablotsky, 2017), demonstrate more clinically impairing features of autism over time (Gray et al., 2012), and exhibit greater challenges with adaptive functioning (Matthews et al., 2015) and navigating social situations (Marriage et al., 2009; Volkmar et al., 1993).

Verbal Communication. Conversational language abilities are highly correlated with intelligence and uniquely contribute to adult outcomes and quality of life. Estimates indicate that more than one third of autistic children will remain non-speaking or minimally verbal throughout their lifespan after receiving years of intervention (National Research Council (US), 2009). The Interagency Autism Coordinating Committee (IACC) highlighted the pressing need to study children with extremely limited verbal abilities who are underrepresented in the behavioral intervention literature (IACC, 2017). A systematic review identified very few interventions geared towards expressive communication for nonspeaking or minimally verbal individuals on the autism spectrum despite the growing demand for EBPs for this population (Koegel et al., 2020). Increasing research has explored the feasibility of Alternative and Augmentative Communication (AAC) devices and barriers to implementation (e.g., Holyfield et al., 2017). However, more research is needed to understand treatment priorities and efficacious treatment approaches for non-speaking individuals.

To understand and address communication difficulties, it is important to consistently define the population in question. A number of terms have been used to refer to individuals with little or no functional speech in the autism research literature, including non-verbal, minimally-verbal, and non-linguistic (Trembath et al., 2019). Recent research proposes distinct classifications for participants who use significantly fewer words than expected relative to age and individuals with more than 50 spontaneous words (Koegel et al., 2020). In this investigation, the term “non-speaking” denotes participants who use no words at all, “single words” includes participants who speak in single words, and “phrases/ sentences” indicates individuals who speak in phrases/ sentences.

The distinction between non-speaking and minimally-verbal in early childhood has implications for development, as preschoolers with even one consistent word seem to have better outcomes than preschoolers with no expressive words (Tager-Flusberg & Kasari, 2013). Longitudinal research suggests that cognitive level is the most important factor related to the development of phrase speech in preschool years, and children classified as non-speaking or minimally verbal are likely to meet criteria for ID (Norrelgen et al., 2015).

The interaction between language and cognitive level continues to influence outcomes into adulthood. Friedman et al. (2019) found that vocabulary diversity (a measure of structural language) and topic maintenance (a measure of social communication) predicted whether adults on the autism spectrum reported having friendships. Furthermore, adults on the autism spectrum with lower IQ reported fewer planned activities, vocational occupations, and friendships than autistic adults with higher IQ, and individuals with lower verbal IQ were less likely to be employed (Lord et al., 2020). These findings highlight the importance of including individuals with language and cognitive delays in research to emphasize unique service needs across the autism spectrum. For instance, treatment services that develop fundamental nonverbal and expressive communication skills could increase the likelihood of meaningful relationships or employment for individuals with profound autism.

Social Functioning. Individuals with profound autism present with unique constellations of social strengths and challenges based on the severity of ID, level of verbal communication, adaptive functioning, vulnerability to sensory overload, and interaction skills. Recent research explored whether youth with ASD + ID were at greater risk for behavior disorders and social skill delays then autistic youth without ID (Baker & Blacher, 2020). Findings indicated that youth with ASD + ID did not demonstrate heightened challenges with social acceptance and social skills, per parent perceptions of social functioning. When examining the spectrum of cognitive abilities, however, lower cognitive ability has been associated with socialization delays in autistic youth, and these findings were not explained by lower social motivation (Itskovich et al., 2021).

Individuals with autism and severe to profound ID may demonstrate increased difficulty navigating a variety of social contexts. In these individuals, social abilities may show little improvement from childhood to adolescence and may decline over time, perhaps due to a lack of ongoing socialization support and opportunities for engagement. Children with severe ID who are passive in their interactions during childhood may appear more aloof in social interactions during adolescence, potentially indicating greater difficulty interacting with peers as social demands increase (Beadle-Brown et al., 2002). In a follow-up of these adolescents in adulthood, the current level of social impairment (classified as socially aloof) was highly predictive of worse outcomes in the domains of life skills, employment, residential placement, and caregiver-reported quality of life (Beadle-Brown et al., 2005). Additionally, delays in social skills may relate to the severity of challenging behavior in profound autism, suggesting that increasing services to promote social communication may improve challenging behaviors (Ingersoll et al., 2017), along with feelings of agency and quality of life (Lachapelle et al., 2005; Nota et al., 2007).

Furthermore, ongoing socialization supports for adults with profound autism could increase working skills, functional communication, social abilities and independence, while decreasing maladaptive behaviors (Schopler, 1994; Siaperas & Beadle-Brown, 2006). More, recent research will reveal families' perceptions of social inclusion, social activities, and socialization EBPs for individuals with profound autism.

Challenging Behaviors and Emotional Wellbeing. Individuals with profound autism are at a higher risk for behavior problems (Garcia et al., 2018; Siegel 2018), and ID severity is a significant predictor of the presence of challenging behaviors (McCarthy et al., 2010). Challenging behaviors range from self-inflicted (e.g., self-injury, head banging) to externalized behaviors (e.g., aggression toward others). These behaviors can interfere with therapeutic sessions and reduce the rate of skill acquisition for individuals with profound autism. Furthermore, challenging behaviors can limit viable options for appropriate school placements and therapeutic services that intend to teach emotional regulation strategies to address these internalized or externalized behaviors (Horner et al. 2002; Mazefsky et al. 2013; Mazurek et al. 2013).

In the absence of appropriate evidence-based practices to support families in managing challenging behaviors, individuals with profound autism may become more emotionally dysregulated and aggressive over time. The prevalence of psychiatric diagnoses, probability of hospitalization, and prescription of psychopharmacological treatments is significantly higher for individuals with ASD + ID than ASD alone (Bertelli, 2019; Cowley et al., 2005; Tsakanikos et al., 2006). Those with profound autism appear to demonstrate significantly more clinical symptomology of anxiety, schizophrenias, stereotypies/tics, self-injurious behaviors, and impulse control when compared to individuals with ID only (Cervantes & Matson, 2015). Some research suggests that individuals ASD + ID tend to use the emergency department more frequently for seizure activity than psychiatric concerns (Hand et al., 2019). This finding may indicate that families have difficulty accessing appropriate mental health supports for individuals with profound autism in emergency department settings. Additionally, prevalent individual characteristics (e.g., severe behaviors, language delays) may overshadow these mental health diagnoses in acute care settings. It is important to explore the ways that challenging behaviors affect service access for families living with profound autism, along with treatment services that may lessen the impact of these behaviors.

Assessment Procedures for Profound Autism

A comprehensive understanding of cognitive, language, social, emotional, and behavioral functioning is integral to evaluating and contextualizing service needs and eventually exploring the efficacy of interventions (Stedman et al., 2019). To date, there is limited research that establishes the validity and reliability of assessment measures for this population. Ethical guidelines suggest that psychologists should use assessment methods that are appropriate to an individual's language competency and whose validity and reliability have been established with members of the population tested (APA, 2017). In this investigation, this process involved carefully defining inclusionary criteria and selecting informant-report measures that aligned with research objectives.

The genetic and developmental overlap between ASD and ID is important to consider when selecting assessments to provide accurate clinical characterization for research participants with profound autism (Fletcher et al., 2016; Thurm et al., 2019). Because both ASD and ID are associated with delays in independent functioning across social, conceptual, and practical domains, clinicians are tasked with determining whether social deficits are attributed to ID, ASD, or a co-occurrence of both diagnoses. In confirming these profiles for adults who were diagnosed with ASD and/or ID in childhood, clinicians may consider conducting structured interviews (e.g. Autism Diagnostic Interview-Revised, ADI-R) with caregivers to determine whether the social communication delays constitute a more significant domain of impairment relative to longstanding developmental delays (Thurm et al., 2019). Additionally, the Diagnostic Behavioral Assessment for Autism Spectrum Disorders-Revised (DiBAS-R; a 19-item screening measure based on caregiver ratings) has been shown to be an adequate autism screening tool for adults with mild to moderate ID (Sappok et al., 2014), although its utility for individuals with severe ID has not been established. These measures provide information regarding social communication, restricted interests, and repetitive patterns of behaviors that are critical to an autism diagnosis.

To capture a live sampling of social communication in a standardized assessment format, the recently validated Adapted Autism Diagnostic Observation Schedule (A-ADOS) may provide more nuanced information about social communication profiles for adults with profound autism and minimally-verbal profiles (Bal et al., 2020). The A-ADOS assesses ASD symptomology in minimally verbal adults by modifying activities intended for children so that they are more engaging for adolescents and adults. For example, instead of using items and tasks that are geared towards infants and children, such as make-believe play, the A-ADOS replaces this activity with an interactive game to better capture an older individual's motivation to communicate and engage. Although findings are preliminary, the A-ADOS shows promising internal consistency and diagnostic validity along with improved specificity for adults with profound autism (Bal et al., 2020). The A-ADOS may be more accurate than the ADI-R or the ADOS-2 for individuals with nonverbal mental ages below 15 months (Risi et al., 2006).

Along with capturing social communication profiles, an accurate assessment of the level of intellectual delays or disability will help to characterize the needs and experiences of individuals with profound autism (Thurm et al., 2019). To assess cognitive functioning, there are several nonverbal cognitive instruments for individuals with lower receptive language and verbal comprehension. These include the Leiter Performance Scale, Third Edition (Leiter-3; Roid et al., 2013), the Comprehensive Test of Nonverbal Intelligence, Second Edition (CTONI-2; Hammill et al., 2009), and the Test of Nonverbal Intelligence, Fourth Edition (TONI-4; Brown et al., 2010). Standardized assessments out of age range may provide age equivalence information regarding an individual's developmental profile. For instance, while the Differential Ability Scales, Second Edition (DAS-II; Elliott, 2007) or the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V; Wechsler, 2003) are standardized instruments used to assess cognitive abilities in children, a clinician may administer these tests with an adult with profound autism to obtain information regarding mental age. This could provide nuanced information on the characteristics of individuals in relation to their service needs and response to treatment.

Because the diagnostic criterion for ID requires co-occurring impairments in adaptive skills (DSM-5-TR, 2022), adaptive functioning measures are another critical component of a profound autism evaluation. Individuals with low cognitive scores often demonstrate impairments in adaptive behavior (Farmer et al., 2020), but so can individuals with average to above average intelligence. Thus, accurate adaptive functioning information is critical to characterize the research sample thoroughly. The two most widely-used adaptive functioning measures include: the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3; Sparrow et al., 2016), which provides information regarding a child's communication, daily living skills, and socialization; and the Adaptive Behavior Assessment System, Third Edition (ABAS-3; Harrison & Oakland, 2015), which assesses adaptive skills such as self-care, responsiveness to others, and the ability to meet environmental demands across the lifespan. Delays in adaptive functioning (e.g., toileting independently) may inform specific treatment goals for individuals with profound autism.

Researchers may also select measures to gather information regarding language level, emotions, and behaviors to characterize the study sample in relation to their service needs. Single word vocabulary tests can be useful as diagnostic or language outcome measures for individuals with limited language, with receptive language tests serving as a proxy for verbal IQ. Kasari et al. (2013) offer a synthesis of measures to capture language skills and related behaviors for minimally verbal children on the autism spectrum. To assess behavioral challenges, researchers may consider measures including the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001), the Emotional Dysregulation Inventory (EDI; Mazefsky et al., 2018), or the Behavioral Assessment System for Children, Third Edition (BASC-3; Reynolds et al., 2015). As there is no widely accepted, validated measure to reliably diagnose co-morbid psychiatric disorders in individuals with profound autism, researchers may utilize an expert consensus process based upon extended observation, caregiver interviews, and record review to assign diagnoses (Siegel et al., 2014). In this process, researchers may also reference the Diagnostic Manual-Intellectual Disability-2 (DM-ID), which was developed to provide clinical insights into the presentations of DSM-5 diagnoses in people with ID (McPherson et al., 2020).

In sum, the appropriate and thorough assessment of individuals with profound autism is critical to determine service needs, treatment research priorities, and ultimately improve services for this population.

Engaging Stakeholders to Improve Services for Profound Autism

Individuals with profound autism and their families engage with service delivery systems for healthcare and therapeutic interventions throughout the lifespan. However, these community service systems are often unprepared to serve individuals with more complex diagnostic presentations. For instance, community mental health systems are rarely equipped to support individuals on the autism spectrum with significant mental health concerns or self-injurious behaviors (Maddox & Gaus, 2019). Some services may use delays in adaptive functioning (e.g., the inability to toilet independently) as a threshold for service exclusion into adulthood.

To improve these service systems, a primary research focus on developing individual-level treatments is unlikely to enhance community participation to bring about systems-level changes in service provision (Shattuck et al., 2020). Rather, it is important to involve a broad array of stakeholders (e.g., families, providers, and teachers) in this process. These stakeholders may provide meaningful contributions throughout all stages of the treatment development process to improve services for individuals with profound autism (Dingfelder & Mandell, 2011). According to Sinclair (2012), one of the original founders of an autistic-run self-help and advocacy group, "Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence" (p. 1). According to some autism advocates, there are important differences between autistic experiences of the world and neurotypical experiences of the world. When individuals with profound autism are unable to verbalize their perspectives, it is important to solicit input from closely aligned stakeholders (caregivers, siblings, close relatives) to ensure that treatment research priorities capture family preferences.

Throughout the research process, *ethical listening* happens when a researcher pays attention to all of the ways that someone is communicating, including speaking and nonspeaking communication (Lebenhagen, 2019). The process of ethical listening may include creative means of incorporating perspectives of individuals with profound autism through drawings or other modes of nonverbal communication (Maes et al., 2021). Parent proxy-report is often considered an appropriate alternative or supplement when reliable self-report is challenged by the presence of complex communication challenges or cognitive impairments (Clark et al. 2015; Dey et al. 2013), as caregivers can provide valuable information regarding an individual's everyday skills and experiences in a variety of contexts (Barokova & Tager-Flusberg, 2020). Furthermore, informant reports constitute an important first step in collaborative practice, whereby the expertise of the caregiver is acknowledged while supporting increased awareness of their priorities (Brady & Keen, 2016).

When clinical researchers embody ethical listening in practice, they explore treatment outcomes that are meaningful and relevant to families. Qualitative interviews with caregiver stakeholders may shed light on the lived experiences of individuals with profound autism and corresponding treatment priorities. For instance, stereotypy is a behavior that interventionists frequently target, yet its reduction may not be a priority intervention goal for the families of individuals with profound autism. The function of stereotypy likely differs based on individual characteristics. For some individuals, the behavior may serve a self-soothing or regulatory function; thus, the reduction of this behavior is not a priority intervention target. Rather, the selection of this treatment target may be a function of how society perceives stereotypy/ self-stimulatory behavior, and is thus less valuable to the individual and their family as an intervention goal (Cunningham & Schreibman, 2008). This example underscores the value of engaging with stakeholders to develop research programs that are relevant and meaningful to families.

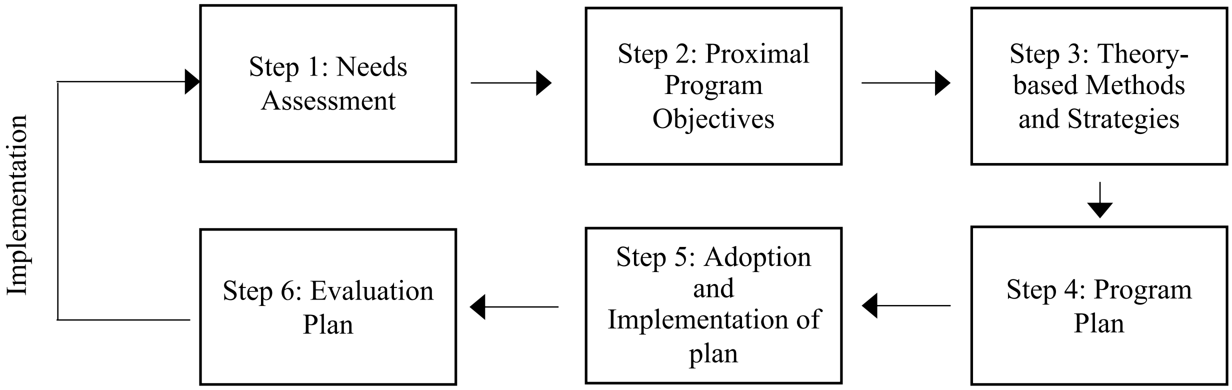
Implementation Methods to Improve Services. A blended approach to systems improvement for individuals with profound autism would incorporate EBPs into care systems and explore the development of new EBPs through implementation science (Lord et al., 2021). Implementation science involves identifying, implementing, evaluating, and disseminating strategies to improve the performance of care systems (Lemire et al., 2017). In other words, implementation science is the study of methods to promote the integration of research into routine practice (Eccles et al., 2011). The designation of profound autism may serve as a gateway to evidence-based, adaptive treatments that are equipped to support individual needs. To realize this goal, a needs assessment is an important first step to establish treatment research priorities that address the diverse and urgent needs of individuals with profound autism.

Selecting and systemically applying the appropriate implementation method depends on a variety of contextual factors (Waltz et al., 2014). Intervention mapping is an example of an implementation method that explicitly incorporates a needs assessment from the onset (Figure 1). It is a systematic, multi-step method for developing interventions that incorporates theory, research, and stakeholder perspectives (Powell et al., 2017; Kok et al., 2016). Intervention mapping begins with a needs assessment to identify associated barriers and facilitators of service access. An exploration of experiences with care delivery systems is an important first step to understanding and addressing barriers to optimal treatment (Maddox et al., 2018). Next, the information gathered from the needs assessment helps to differentiate the target population (subgroups) and guides the selection of program components and proximal program objectives for that subgroup. Ideally, community stakeholders provide firsthand perspectives to guide the selection of goals and priorities. Third, the research team generates a list of intervention methods based on proximal program objectives. Researchers may continue to collaborate with community stakeholders at this step to develop and delineate intervention methods and then translate those methods into strategies. Fourth, a program plan operationalizes the intervention strategies, including what they entail and how they will be delivered. Fifth, the research team designs an implementation strategy that specifies the adoption and implementation of program objectives.

Program materials such as the implementation intervention manual are designed and refined with feedback. Finally, intervention and implementation progress is monitored and evaluated through an established evaluation plan (Eldredge et al., 2016; Powell et al., 2017).

Figure 1

Intervention Mapping Process



Intervention mapping is inherently participatory and has the potential to unite stakeholders around commonly shared goals with opportunities to provide ongoing feedback on the implementation approach. It has been used to develop health-related programs, including sex education (Schaafsma et al., 2013) and cardiovascular health (Mani et al., 2013). When developing an implementation strategy that incorporates a needs assessment, researchers may also consider following a five phase plan that begins with hypothesis development and methods (Phase 1 and 2), continues into controlled intervention trials (Phase 3 efficacy), and then population effectiveness (Phase 4 effectiveness), and ends with demonstration and implementation (Phase 5; Proctor et al., 2009). In this process, a needs assessment could be conducted throughout phases 1 and 2 to inform hypothesis development and methods (Proctor et al., 2009). While there is theoretical and empirical support for these dissemination models, some researchers critique linear models of dissemination, highlighting that ongoing consultations with stakeholders may impede linear progression through the model (Addis, 2002). However, in both models presented, program planners may alternate between tasks and steps to address the needs of a community.

As an integral component of implementation science, qualitative methods are a category of research approaches that produce findings without reliance on quantitative measurement or statistical measurement (Hamilton et al., 2013). Qualitative research is critical for documenting stakeholder priorities for research, and then the contexts in which interventions are implemented, the process that occurs during implementation, and the effectiveness of implementation strategies (Hamilton & Finley, 2019). Mixed method designs further the goals of implementation science by providing unique insights into service access, quality, and delivery. To address the dearth of research characterizing services for adolescents and adults with profound autism in the United States, this investigation implemented a mixed methods study design to identify initial care improvement targets.

A prominent example of implementation methods in the autism research literature is the development of an *Individualized Mental Health Program for Children with ASD*, or AIM HI, a package of evidence-based intervention strategies designed to reduce challenging behaviors in children (5-13 years) on the autism spectrum (Brookman-Frazee & Drahota, 2010). Initially, a community needs assessment and a review of the literature on evidence-based mental health interventions for youth on the autism spectrum identified the need for the AIM HI intervention package (Baker-Ericzén et al., 2010; Brookman-Frazee et al., 2012; Brookman-Frazee et al., 2010; Brookman-Frazee et al., 2009). Researchers and autism experts then collaborated with community stakeholders to create the manual and therapist training materials. Materials were refined based on therapist and parent feedback in a pilot study (Brookman-Frazee et al., 2012;

Drahota et al., 2014; Stadnick et al., 2013) and then AIM HI was further evaluated and refined through a cluster randomized clinical trial (Brookman-Frazee & Stahmer, 2018).

Ongoing quantitative, qualitative, and mixed methods evaluations of AIM HI lend new insights into psychiatric comorbidities for autistic children with autism serviced within publicly funded mental health programs to improve access to appropriately tailored interventions (Brookman-Frazee et al., 2018). Additionally, ongoing evaluations assess attitudinal and organizational barriers to successful adoption of these strategies by community providers (Dyson et al., 2017; Dyson et al., 2019) and ways to adapt intervention strategies for Latinx clients (Chlebowski et al., 2020). Researchers and community stakeholders continue to revisit steps of the implementation process and to engage critically with the program to maintain the effectiveness of the AIM HI intervention package in "real world" treatment settings.

Similarly, there is a dearth of knowledge about service delivery systems for individuals with profound autism and stakeholders' priorities for improving these services. As discussed, intervention mapping provides one path from the identification of service needs to the recognition of programs that may present a solution. An exploration of experiences with care delivery systems is an important first step to understanding and addressing barriers to optimal treatment for individuals with profound autism. The feedback provided by caregivers through qualitative and quantitative reports will inform treatment research objectives for this population.

Chapter Three: Methods

Research Design

This study used a mixed-methods design to incorporate the perspectives of potential consumers of EBPs for profound autism using a QUAN -> QUAL framework with sequential data collection and equal weighting of data in analyses (Palinkas et al., 2011). The qualitative data provided an important means of triangulation by clarifying quantitative data and expanding through caregiver narratives, and the data was merged for the primary purpose of exploration and hypothesis generation (Palinkas et al., 2011; Stadnick et al., 2013). Quantitative methods initially measured clinical characteristics of adolescents and adults with profound autism, along with patterns of service utilization, barriers to service access, and service priorities. Interview informants were selected based on responses to the survey questionnaire. A purposeful sampling strategy for qualitative participants complemented the quantitative sample to increase the quality of inferences (internal validity) and the generalizability of findings (external validity; Palinkas et al., 2015). Qualitative methods captured the richness and diversity of caregivers' service needs and treatment priorities. These methods are particularly appropriate for gathering in-depth, subjective experiences (Marshall & Rossman, 2014).

Recruitment

To capture a breadth of experiences, survey respondents were recruited nationwide through partnerships with the National Council on Severe Autism and Autism Science Foundation, organizations serving adolescents and adults with profound autism, targeted social media postings, and email listservs. Survey respondents were from California (14.2%), North Carolina (6.9%), Texas (5.2%), Florida (4.7%), New York (4.5%), Pennsylvania (4.3%), Illinois (3.8%), Washington (3.3%), New Jersey (3.3%), Massachusetts (3.1%), and Georgia (3.1%). The remaining 36 states were represented by less than 3.0% of respondents.

Qualitative interviews were conducted with a subset of 20 caregivers who completed the survey. Interviewees were selected by maximum variation sampling, a purposeful sampling method that selects cases for documenting unique variations that have emerged in adapting to different conditions, as well as to identify common patterns and themes that cut across variations.

Embedded in this strategy is the ability to identify similarities and differences in the phenomenon of interest (Palinkas et al., 2015). In this study, the sampling criteria selected were variation in state of residence, racial/ethnic diversity, and SES (as captured by income or caregiver educational status reported on the survey). Interview respondents were from California (35.0%), North Carolina (15.0%) and Michigan (10.0%). The remaining interview respondents were represented equally from Arizona, Florida, Indiana, New York, New Jersey, Massachusetts, Pennsylvania, and Texas (5%).

Participants

Eligible survey participants included parents or other legal guardians (18 years or older) of adolescents and adults (12 years or older) with autism and high support needs who were U.S. residents. Given the variability in descriptors that caregivers use for their child on the autism spectrum and the recent introduction of profound autism, the designation "with autism and high support needs" was defined for caregivers at the screening stage of the survey to include individuals with *intellectual delay/ disability, minimal verbal ability, and/or requires substantial support in daily life*. Overall, 720 caregivers provided informed consent to start the online survey. Of those, 297 caregivers were either ineligible after screening or only partially completed the survey, yielding a final quantitative sample size of 423. Families who were ineligible to participate received an automated message thanking them for their time, reiterating inclusion criteria, and providing a link to resources.

Survey respondents were primarily mothers (81.6%), followed by fathers (17.5%) and other legal guardians (0.9%). The mean age of their children with autism and high support needs was 18.89 (*SD* = 6.29), and caregivers reported a mean age of 5.15 years (*SD* = 6.29) when their child received an ASD diagnosis. When reporting on diagnoses, 67.8% of caregivers reported that their child has co-occurring ID. The majority of caregivers identified their child's sex as male (74%), followed by female (26.7%), and intersex (0.2%). Interview participants were primarily mothers (85.0%), followed by fathers (10%), and one legal guardian (5.0%). Interview respondents were reporting on individuals with a mean age of 19.15 years (*SD* = 10.13, range = 12-53). Of the interview participants, caregivers reported that 65.0% of their children had co-occurring ID and 75% were nonspeaking or spoke in single words only. Within the interview sample, 40% of caregivers identified as White or Caucasian, 20% of caregivers identified as Black or African American, 35% identified as Multiracial, 5% identified as Asian American, and 50% identified as Hispanic or Latinx. The majority of interview participants indicated that their combined family income fell in the $25,000 – $50,000 range, though income ranged from less than $14,999 to $200,000 and greater. Demographics for the survey and interview sample are included in Table 1.

Table 1

Child and Caregiver Demographics of Survey and Interview Participants

		Survey Sample	Interview Sample
Child Gender			
	Male	306 (72.3%)	11 (55%)
	Female	115 (27.2%)	9 (45%)
	Transgender/Gender variant/nonconforming	2 (0.4%)	0 (0%)
Race/Ethnicity*			
	Asian or Asian American	28 (6.6%)	1 (5%)
	Black or African American	26 (6.1%)	4 (20%)
	Middle Eastern	14 (3.3%)	0 (0%)
	Native American, American Indian, or Alaskan Native	22 (5.2%)	0 (0%)
	Native Hawaiian or Pacific Islander	22 (5.2%)	0 (0%)
	White or Caucasian	329 (77.8%)	8 (40%)
	Other Race/ Multiracial	25 (5.9%)	7 (35%)
	Hispanic or Latino/a/x	95 (22.5%)	10 (50%)
Communication			
	No words at all	96 (22.7%)	6 (30%)

	Single words (1-10 words)	99 (23.4%)	3 (15%)
	Single words (11+ words)	84 (19.9%)	6 (30%)
	Short phrases (2-3 words together)	109 (25.8%)	2 (10%)
	Full sentences	35(8.3%)	3 (15%)
Co-morbid Diagnoses*			
	Intellectual Disability	287 (67.8%)	13 (65%)
	Mood Disorder	188 (44.4%)	10 (50%)
	ADHD	121 (28.6%)	4 (20%)
	Seizures/ Epilepsy	112 (26.5%)	6 (30%)
	Genetic Disorder	50 (11.8%)	0 (0%)
Caregiver Education			
	Less than High School	12 (2.9%)	0 (0%)
	High School graduate	38 (9.2%)	2 (10%)
	Some college	78 (18.9%)	8 (40%)
	Associate’s degree	58 (14.0%)	1 (5%)
	Bachelor’s degree	129 (31.2%)	3 (15%)
	Master’s degree	80 (19.4%)	5 (25%)
	Doctoral or Professional degree	18 (4.4%)	1 (5%)
Combined Family Income			
	Less than $14,999	10 (2.4%)	1 (5%)
	$15,000 through $24,999	24 (5.7%)	2 (10%)
	$25,000 through $49,999	73 (17.3%)	7 (35%)
	$50,000 through $74,999	82 (19.4%)	2 (10%)
	$75,000 through $99,999	63 (14.9%)	3 (15%)
	$100,000 through $124,999	55 (13.0%)	0 (0%)
	$125,000 through $149,999	22 (5.2%)	1 (5%)
	$150,000 through $174,999	30 (7.1%)	1 (5%)
	$175,000 through $199,999	11 (2.6%)	0 (0%)
	$200,000 and greater	45 (10.6%)	3 (15%)
	Don't know	8 (1.9%)	0 (0%)
Health Insurance*			
	Private Health Insurance	208 (49.2%)	11 (55%)
	Medicaid, State, or Federal insurance program	296 (70.0%)	14 (70%)
	Self-Pay	123 (29.1%)	4 (20%)
	No health care services	15 (3.5%)	0 (0%)
	Other	9 (2.1%)	0 (0%)

Note. Asterisk indicates that participants could check all that apply.

Procedure

The study received Institutional Review Board approval from the University of California, Santa Barbara. Survey data were collected and managed using REDcap electronic data capture tools with the Google reCAPTCHA feature enabled to protect the survey from spam and abuse (Harris et al., 2009; Harris et al., 2019). The survey included three sections related to clinical profile, service access and barriers, and service priorities (Appendix A). Caregivers were entered into a lottery to win one of five $25 gift-cards for completing the survey.

At the end of the survey, participants were asked whether they would be willing to participate in a supplemental interview. Interview participants received a $40 gift-card for participation in the hour-long interview. Interviews were conducted by one graduate student researcher with expertise in the profound autism population.

Of the 423 who completed the survey, 309 participants indicated that they would be willing to be interviewed (73%). Using the sampling method described above, invitations to interview were sent to 70 participants, with one reminder to those who did not reply to the initial invitation. Interview participants were iteratively sampled to monitor diversity of experiences, common themes, and depth of data (Hennink et al., 2017). The sample size of 20 interview informants was theoretically grounded in thematic saturation of data, which refers to the point at which data begin to repeat and further data collection becomes redundant (Kerr et al., 2010). It has been found that theoretical meaning saturation is often achieved between 16-24 interviews once themes have been identified and conceptually understood (Hennink et al., 2017).

Measures

Background. Initially, respondents reported on logistical, demographic, and personal characteristics via online questionnaire. These questions included their specific relationship to the adolescent or adult, socioeconomic status, health insurance, and highest level of completed education. Respondents then reported on the age, sex, gender, race, and ethnicity of the adolescent/adult as well as characteristics including language level, living and employment situation, and co-occurring diagnoses (Table 1). These questions were adapted from prior studies assessing service needs and priorities amongst autistic adults (Gotham et al., 2015; Pellicano et al., 2014; Schott et al., 2021).

Emotion Regulation. Schalock et al.'s (2002) review of quality of life for individuals with ID notes that emotional well-being is an important domain of overall wellbeing. The Emotion Dysregulation Inventory (EDI; Mazefsky, Day, et al., 2018; Mazefsky, Yu, et al., 2018) is an informant report measure of emotion dysregulation, or emotional distress and problems with emotion regulation, that is currently normed for individuals aged 6 years and older. Caregivers rated items on a five-point scale based on their child's behavior over the past 7 days from 0 (not at all) to 4 (very severe). The EDI yields separate scores for *Reactivity*, or rapidly escalating, intense, and poorly regulated emotional responses (characterized by anger/irritability) and for *Dysphoria,* or sadness, unease, low motivation, and anhedonia. The short form of the EDI includes 13-items total, with 7 items for Reactivity and 6 items for Dysphoria. The EDI has been found to have good reliability in samples of individuals across the spectrum of ASD, including individuals with ID ($\alpha = 0.94$; Conner et al., 2018). EDI raw scores for Reactivity and Dysphoria were converted to *t*-scores using a clinical (ASD) normative sample (Mazefsky et al., 2018). In the present study, the mean reactivity *t*-score ($n = 423$) was 52.26 ($SD = 9.14$) and the mean dysphoria *t*-score was 55.82 ($SD = 9.38$). For reactivity, t-scores above 46.9 are considered clinically elevated, whereas t-scores above 52.2 are considered clinically elevated for dysphoria in the ASD normative sample.

Waisman Activities of Daily Living Scale (W-ADL). The W-ADL measures the level of independence in activities of daily living in adolescents and adults with intellectual and developmental disabilities (Maenner et al., 2013). It lists 17 activities that are rated on a three-point scale by a caregiver or someone who knows the individual well. The scale ranges from 0 (does not do at all), 1 (could do but does not/does with help), and 2 (does independently). The 17 item scores are summed to create a total W-ADL score, with higher scores indicating better daily living skills. Items encompass a wide range of skills that are critical for independent living, including toileting, dressing, making the bed, preparing a meal, doing laundry, and managing daily finances. The W-ADL has been validated in studies involving individuals with ASD + ID. It has an alpha internal consistency coefficient of 0.88–0.92, and is reliable over time and between respondents (Maenner et al., 2013). In an autism sample, the W-ADL measure was highly correlated with the Vineland-3 Adaptive Behavior Composite Score ($r = 0.78$; Maenner et al., 2013). In the present sample, the mean W-ADL score was 14.15 ($SD = 6.52$).

Service Needs and Barriers. Survey question items related to services currently received, perceived service needs, and barriers to service access were based on the PA Autism Needs Assessment (www.paautism.org/needsassessment), a survey that has been implemented twice to autistic individuals of all ages and their families in Pennsylvania (Schott et al., 2021). Respondents were presented with the question, “Please tell us about your child’s current specialty service needs” and selected from the options: My child is receiving; my child is not receiving, but needs; my child is not receiving, and does not need. This investigation included 12 options for services currently received (e.g., social clubs/ activity groups, vocational/ job training, mental health counseling). Caregivers endorsed whether their child received more of these services when they were younger (“yes” or “no”) to ascertain whether there has been a decline in services. Caregivers then endorsed their barriers to service access, including transportation, scheduling, child’s behavior problems, shortage of service providers in the area, no service providers in the area, unsatisfied with service providers in my area, cost of services/ my insurance doesn’t cover, or a decline or loss in services during COVID-19.

Receipt of services were coded for “my child is receiving” and unmet needs were coded for “my child is not receiving, but needs” for each service category to create a binomial outcome variable. The number of unmet service needs was summed for “my child is not receiving, but needs” across all service categories to create a total score of unmet needs ($M = 5.22$, $SD = 2.62$, range = 0 – 12).

Service Priorities. The items related to service priorities were adapted from a mixed-methods study that explored the priorities for autism research from the perspective of autistic adults, family members, practitioners, and researchers (Pellicano et al., 2014). The service priorities for this investigation were based on the core and co-morbid symptoms of autism included in the Autism Parenting Stress Index (Silva & Schalock, 2012), the PA Autism Needs Assessment, and components of a social skill program for adults with profound autism (Ferguson et al., 2021). Caregivers were presented with the following prompt: “We’re interested in identifying skills and competencies that are most important to you and your family to develop better services for adults with autism and high support needs. To help us design better services, we are asking you to rate the importance of your child receiving support to improve each skill below, regardless of whether your child currently uses the skill or not.” Participants ranked the importance of each skill on a 5-point scale from *1* = not important at all to *5* = very important. Sample items included indicating when they are hurt or sick, increasing verbal communication, recognizing emotions and calming down when upset.

Semi-Structured Interview Guides

The interview guide was shaped by the conceptual framework of the study to complement, clarify, and expand upon findings from the quantitative survey (Holtrop et al., 2018). The interview was semi-structured, meaning that the interviewer could adopt a conversational style and adjust the order of the specified questions as appropriate. The guide included questions tailored to the expertise and role of caregivers within service systems for their child with profound autism. The questions were grounded in the aim of identifying caregivers' experiences navigating service systems (Appendix B). Questions were also developed through consulting an interview guide designed to improve access to community treatment for adults on the autism spectrum with co-occurring psychiatric disorders (Maddox et al., 2020), along with qualitative studies that have assessed autism treatment needs (Pellicano et al., 2014; Tschida et al., 2021) and therapists' perspectives on treatment delivery (Barnett et al., 2021).

The interviews followed a funnel approach, with broad inquiries followed by specific follow-up questions to clarify and illuminate details from participant narratives (Spradley, 1979). Guidance on qualitative questions suggests expressing them as openly and clearly as possible, without making assumptions about how participants might think or feel (Braun et al., 2020). Three initial interviews were conducted to test and refine the flow, intelligibility, and relevance of the interview protocol (Kallio et al., 2016).

Opening and Service Needs. As part of a brief initial review of background characteristics gathered from the survey, the interviewer inquired about living situation, health insurance status, and school/employment to build rapport. The interviewer then asked the caregiver to "Tell me about your experiences getting help for your child." The primary objective of the opening question was to encourage caregivers to share about their experiences in a meaningful, exploratory, and focused manner (Spradley, 2016; Spradley, 1979). The interviewer then asked questions to learn more about the caregiver's experiences accessing specialized services, programs, or activities for their child. The interviewer asked a guiding question to learn more about the nature of the caregiver's service needs: "What types of services does your child need that they are not currently receiving?" If indicated, the interviewer encouraged the caregiver to elaborate upon their reasons for needing these services and perceived benefit of these services.

Barriers to Service Access. The interviewer explored barriers to service access by asking caregivers to elaborate upon their treatment needs and to describe any difficulties on the path to obtaining services for their child (e.g., "What challenges have you faced in getting help for your child?"). If caregivers did not reference specific barriers through their answers to open-ended questions about accessing services, then the interviewer inquired more specifically about services available in their community, transportation, cost of services, decline in services over time, or the impact of the COVID-19 pandemic.

Treatment Needs and Service Priorities. The interviewer explored intervention priorities by asking the caregiver to describe the top skills that they hope their child learns in the coming years, along with strategies that have been helpful for teaching their child new skills. The interviewer also inquired about the types of supports that the parent/ caregiver needs to navigate service systems for their child. Across several implementation studies, researchers have found it useful to ask a question that encourages the participant to imagine the ideal situation (Hamilton & Finley, 2019). The interviewer asked the caregiver to envision their model supports for their child to capture key service priorities ("Imagine that you could create your ideal support service for your child. What would it be and why?"). The interviewer also asked about hopes and dreams for the future. Finally, Braun et al. (2020) recommend ending with an open-ended question, which can generate unanticipated and useful data. The final open-ended question asked caregivers whether they wanted to share additional thoughts about their service needs or hopes for the future.

Chapter Four: Results

Quantitative Data Analysis

Data was screened for invalid response patterns and incomplete responses in primary variables of interest were excluded. First, descriptive statistics (*M, SD,* and percentage of the total sample) provided information about the study population, met and unmet service needs, barriers to service access, and service priorities. Correlations (*r*) determined associations between independent continuous variables to rule out multicollinearity (Table 2; Mansfield & Helms, 1982).

A Poisson Regression was conducted to explore demographic variables (age, race, ethnicity, and SES) as predictors of the sum of unmet service needs. Initially, the dependent variable (sum of unmet service needs) was screened to ensure that the mean and variance were similar ($M = 5.22$; Variance = 6.85; Coxe et al., 2009). Binomial logistic regressions were conducted to ascertain the effects of demographic and clinical characterization variables on the likelihood of unmet service needs (dummy coded with "my child is receiving" as the reference category; "my child is receiving" = 0, "my child is not receiving, but needs" = 1) for the top six services with the greatest frequency of unmet needs. For each binomial logistic regression model, data were screened for significant outliers (standardized residuals) that may reduce the predictive accuracy of results (Hilbe, 2016). Predictor variables for each logistic regression included: EDI reactivity and dysphoria *t*-scores; W-ADL total score; SES (continuous variable); ethnicity (0 = not Hispanic/ Latino/a/x, 1 = Hispanic/ Latino/a/x); and language level (no words, single words, phrases/sentences). Although important information is lost when aggregating racial identities (e.g., all individuals who identified a race other than White/Caucasian), this recoding allowed the inclusion of race in the quantitative model given limited diversity in the sample. Regarding language level, caregivers endorsed “no words at all”, “usually speaks in single words (1-10)”, “usually speaks in single words (11+)”, “usually speaks in short phrases (2-3 words)”, or “usually speaks in full sentences.” For analytic purposes, the two single word categories and the phrases and sentences categories were combined to create three categories (no words, single words, phrases/ sentences) and “no words” was used as the reference category.

Table 2

Correlation Matrix

	Child Age	Unmet Needs Sum	W-ADL Sum	EDI Dysphoria *t*-score	EDI Reactivity *t*-score	SES	*M*	*SD*
Child Age	--						18.96	6.29
Unmet Needs	.07	--					5.22	2.62
W-ADL	-.08	.04	--				14.15	6.52
EDI Dysphoria	-.24**	.22**	.10*	--			55.82	9.38
EDI Reactivity	-.08	.16**	-.13**	.55**	--		52.26	9.14
SES	.15**	-.16**	.004	-0.11*	.002	--	5.28	2.42

*p<0.05 (two-tailed)
**p<0.01 (two-tailed)

Qualitative Data Analysis

All semi-structured interviews were digitally recorded and professionally transcribed verbatim. Rapid qualitative assessment methods were used to analyze the interviews (Hamilton, 2013; Hamilton & Finley, 2019; Hamilton, 2020). Rapid qualitative analysis is an approach that balances rigor and efficiency to expedite the dissemination of qualitative findings. This method has been found to yield comparable findings in direct comparison to other established qualitative approaches, such as thematic analysis (Gale et al., 2019; Nevedal et al., 2021;Taylor et al., 2018).

Rapid qualitative analysis involves the following phases (Hamilton, 2020). First, the lead author created a neutral domain name that corresponded with each interview question. Then, the lead author drafted a “summary template” to organize responses to interview questions under corresponding domain names. The lead author trained summarizers to document key statements from the interviews through a minimally interpretive process. Next, the team (consisting of the lead author and two summarizers) piloted the template with a subset of transcripts to ensure that the domains were intuitive for the data and to establish consistency between summarizers. A section at the end of the two-page summary template provided space for other information that was not relevant to pre-established domains. Summarizers recorded the absence of data by noting whether a question was omitted or incomplete. After consistency was established, the team divided the transcripts and summarized in an organized and thorough manner (Hamilton, 2013). The lead author audited all summaries to ensure consistency and readability.

Finally, the summaries were transferred to a matrix (respondent by domain) to facilitate the process of systematically noting similarities, differences, and trends by respondents (Averill, 2002). The research team iteratively reviewed the summary matrix across interviews and by interview question to develop themes pertaining to each domain. They also extracted illustrative quotations for each theme (Harkness et al., 2022).

The lead author then assessed whether the themes reflected the meanings evident in the data set as a whole. Qualitative analysis was driven by the study’s conceptual framework, representing a deductive approach in which framework domains are used to categorize narrative data (Hamilton & Finley, 2019). The analytic process incorporated an inductive approach with findings that were unexpected or new features learned from the data. Research shows that inductive and deductive approaches are not mutually exclusive (Fereday & Muir-Cochrane, 2006).

Integration of Quantitative and Qualitative Findings

The functions of this mixed-methods design were: 1) Convergence, or triangulating results to see if quantitative ratings of unmet service needs and priorities yielded similar conclusions as qualitative reports; 2) Complementarity, or deepening the understanding of quantitative data with qualitative narratives; 3) Expansion, or further illuminating the meaning of quantitative results with qualitative data (Palinkas et al., 2011). The qualitative component of this study identified salient themes regarding service needs and priorities to complement and expand upon quantitative findings. The final stage of qualitative analysis included producing this empirical synthesis in the form of a scientific report to provide a coherent and vivid account of the data in relation to the research questions (Braun & Clarke, 2006).

Main Findings: Quantitative Results

Four hundred and twenty-three caregivers reported on services their child was either receiving, not receiving but needs, or not receiving and does not need (Table 3). Social clubs/activity groups were the most frequently endorsed unmet service need, with 60.3% of caregivers reporting that their child needed this type of service. This was followed by primary health care services with autism-specific training (59.3%), social skills training (55.8%), life skills training (51.3%), occupational therapy (49.2%), and behavioral support (47.3%). The least commonly endorsed service needs were mental health counseling (30.0%) and sexual health education (27.0%). When asked whether their child received some or all of these services when they were younger, 79.0% of caregivers endorsed *yes*, suggesting a decline in services as their child entered adolescence or adulthood.

Table 3

Patterns of Service Needs Ordered by Endorsement of Need

Services (*n* = 423)	Receiving (%)	Not receiving but needs (%)	Not receiving and does not need (%)
Social Clubs/Activity Groups	24.1	60.3	15.6
Primary Health Care Services	26.5	59.3	14.2
Social Skills Training	29.6	55.8	14.7
Life Skills Training	39.0	51.3	9.7
Occupational Therapy	27.7	49.2	23.2
Behavioral Support	36.2	47.3	16.5
Speech and Language Therapy	40.7	43.3	16.1
Vocational Training	15.4	39.0	45.6
Case Management	48.7	38.5	12.8
Mental Health Counseling	24.8	30.0	45.2
Sexual Education	11.8	27.0	61.2
Other Service	10.2	21.3	22.7

Next, caregivers selected barriers to accessing these services for their child. Shortage of service providers in the area (61.9%) was the most frequently endorsed barrier, followed by child behavior problems (54.1%), COVID-19 resulting in decline or loss of services (37.8%), cost of services/insurance doesn’t cover (35.5%), no service providers in the area (29.1%), unsatisfied with service providers in the area (27.2%), scheduling (23.6%), transportation (15.8%), or other barriers (7.1%).

Finally, caregivers reported on their priority treatment targets for their child (Table 4). Indicating when they are hurt or sick was a top priority, with 61.7% of caregivers reporting that this was a "very important" skill for their child to learn. This was followed by recognizing emotions and calming down when they are upset (56.5% caregivers), decreasing aggressive or self-harm behaviors (55.8% of caregivers), requesting things that they need or want (51.1% of caregivers), practicing independent living skills (48.9% of caregivers), and increasing verbal communication (48.2% of caregivers).

Table 4

Treatment Priorities Ordered by Endorsement of Relative Importance

Rate the importance of your child receiving support to improve each skill:	Not Important (%)	Important (%)	Very Important (%)
Indicating when they are hurt or sick	1.7	11.3	61.7
Recognizing emotions and calming down when they are upset	1.7	12.5	56.5
Decreasing aggressive or self-harm behaviors	5.7	12.1	55.8
Requesting things that they need or want	1.7	14.7	51.1
Practicing independent living skills	0.9	15.4	48.9
Increasing verbal communication	5.7	12.8	48.2
Increasing physical activity/exercise	3.1	15.4	37.4
Training in using AAC devices	11.6	18.2	32.9
Developing and maintaining friendships	4.0	25.8	31.4
Practicing social skills	2.1	26.2	27.7
Finding and maintaining a job	21.0	23.9	13.0
Developing skills for romantic relationships/dating	34.3	18.0	8.7

Predictors of Unmet Service Needs

A Poisson Loglinear Regression was conducted to look at child's age, race, ethnicity, and SES as predictors of the total number of unmet service needs (*n* = 415), and SES emerged as the only significant predictor (Table 5). For every one unit increase in SES, there was a 3.7% decrease in the number of unmet needs, controlling for other variables in the model (*B* = -.04, CI: -.06 to -.02, *p* <.001). Child's age was positively but not significantly associated with unmet needs, such that unmet needs increased by 0.5% for every one unit increase in age, controlling for other variables in the model (*p* = .12). Caregivers who did not identify as White were 0.9% more likely to have unmet needs than caregivers who identified as White, controlling for all other variables in the model (*p* = .87).

Table 5

Predictors of Sum of Unmet Service Needs

			85% Wald Confidence Interval		Hypothesis Test				95% Wald C.I. for Exp(*B*)	
	B	Std. Error	Lower	Upper	Wald-Chi Square	*df*	*p*	Exp(*B*)	Lower	Upper
Latino/a/x	-0.90	.06	-0.20	.02	2.45	1	0.118	0.91	0.82	1.02
Non-White	.01	.05	-0.10	0.11	.03	1	0.870	1.01	0.91	1.12
Age	.01	.004	-.001	.01	2.41	1	0.121	1.01	1.00	1.01
SES	-.04	.01	-.06	-.02	16.17	1	<.001	0.96	0.95	0.98

Note: The "Non-White" variable includes participants who selected a race other than White/ Caucasian, with White as the reference category. The reference category for "Latino/a/x" includes participants who did not identify as Latino/a/x.

Social Clubs/ Activity Groups. A logistic regression was performed to ascertain the effects of EDI reactivity and dysphoria *t*-scores, W-ADL total score, language level, SES, age, and ethnicity on the likelihood that caregivers reported an unmet service need for social clubs/ activity groups (*n* = 357). There were four standardized residuals with values above 2.5 standard deviations, which were kept in the analysis. The model explained 18.1% (Nagelkerke R^2) of the variance in unmet service needs and correctly classified 74.2% of cases ($\chi^2(8) = 46.92$, $p < .001$). The odds of needing social clubs/ activity groups were 4.92 times greater for caregivers of individuals who spoke in single words relative to caregivers of children with no words, controlling for all other variables in the model ($B = 1.59$, $p = .002$). Caregivers of individuals who spoke in phrases/sentences had 6.51 times higher odds of reporting this service need than caregivers of children with no words, controlling for all other variables in the model ($B = 1.87$, $p < .001$). Caregivers of individuals who identify as Hispanic/Latino had 2.14 times higher odds of reporting the need for social clubs/ activity groups than caregivers who did not identify as Hispanic/Latino, controlling for all other variables in the model ($B = 0.76$, $p = .014$). Increasing EDI reactivity *t*-scores corresponded with an increased likelihood of needing social club/activity groups ($B = .05$, $p = .015$), and increasing SES was associated with a decreased likelihood of needing these services ($B = -.13$, $p = .015$; Table 6).

Table 6

Logistic Regression Predicting Likelihood of Unmet Social Club Needs

							95.0% CI for Odds Ratio	
	B	SE	Wald	*df*	*p*	Odds Ratio	Lower Bound	Upper Bound
Age	.01	.02	0.17	1	0.677	1.01	0.97	1.06
W-ADL	-.02	.02	0.78	1	0.378	0.98	0.94	1.02
EDI Dysphoria	-.01	.02	.08	1	0.782	1.00	0.96	1.03
EDI Reactivity	.05	.02	5.96	1	.015	1.05	1.01	1.09
Ethnicity	0.76	0.31	6.02	1	.014	2.14	1.17	3.94
SES	-0.13	.06	5.97	1	.015	0.87	0.79	0.97
Single Words	1.59	0.52	9.38	1	.002	4.92	1.77	13.63
Phrases	1.87	0.53	12.72	1	<.001	6.51	2.33	18.21
Constant	-2.84	1.37	4.30	1	.038	0.06	-	-

Primary Health Care Services with Autism-Specific Training. A logistic regression was performed to ascertain the effects of EDI reactivity and dysphoria *t*-scores, W-ADL total score, language level, SES, age, and ethnicity on the likelihood that caregivers reported an unmet service need for primary health care services with autism-specific training (*n* = 356). No outliers were identified. The model explained 6.7% (Nagelkerke R^2) of the variance in unmet service needs and correctly classified 69.9% of cases ($\chi^2(8) = 17.24$, $p = .028$). SES emerged as the only significant predictor. Every one unit increase in SES was associated with 0.86 times decrease in the odds of needing primary health care services with autism-specific training, controlling for all other variables in the model ($B = -.16$, $p = .002$; Table 7).

Table 7

Logistic Regression Predicting the Likelihood of Unmet Primary Healthcare Needs

							95.0% CI for Odds Ratio	
	B	SE	Wald	*df*	*p*	Odds Ratio	Lower Bound	Upper Bound
Age	.01	.02	0.16	1	0.687	1.01	0.97	1.05
W-ADL	-.02	.02	0.76	1	0.385	0.98	0.94	1.02
EDI Dysphoria	.00	.02	.02	1	0.881	1.00	0.97	1.04
EDI Reactivity	.00	.02	.06	1	0.800	1.00	0.97	1.04
Ethnicity	.01	0.32	.00	1	0.975	1.01	0.54	1.89
SES	-0.16	.05	9.41	1	.002	0.86	0.78	0.95
Single Words	0.51	0.34	2.31	1	0.129	1.67	0.86	3.24
Phrases	-0.18	0.36	0.26	1	0.608	0.83	0.41	1.68
Constant	1.24	1.15	1.15	1	0.283	3.44	-	-

Social Skills Training. A logistic regression indicated that EDI dysphoria *t*-scores, SES, and age were significantly associated with the likelihood that caregivers reported an unmet service need in social skills training, controlling for all other variables in the model (*n* = 355). There were three standardized residuals with values above 2.5 standard deviations, which were kept in the analysis. The model explained 15.8% (Nagelkerke R^2) of the variance in unmet service needs and correctly classified 69.3% of cases ($\chi^2(8) = 43.21$, $p < .001$). Every one unit increase in child's age was associated with 1.10 times increase in the odds of needing social skills training, controlling for all other variables in the model (*B* = .10, $p < .001$). For each one unit increase in SES, the odds of needing social skills training decreased by a factor of 0.82 (*B* = -0.20, $p < .001$). Increasing EDI dysphoria *t*-scores were associated with an increased likelihood of needing social skills training (*B* = .03, $p = .044$; Table 8).

Table 8

Logistic Regression Predicting the Likelihood of Unmet Social Skill Service Needs

							95.0% CI for Odds Ratio	
	B	SE	Wald	*df*	*p*	Odds Ratio	Lower Bound	Upper Bound
Age	0.10	.03	14.29	1	<.001	1.10	1.05	1.16
W-ADL	-.01	.02	0.15	1	0.703	0.99	0.95	1.03
EDI Dysphoria	0.03	.02	4.07	1	.044	1.03	1.00	1.07
EDI Reactivity	0.02	.02	1.14	1	0.286	1.02	0.99	1.05
Ethnicity	0.15	0.30	0.24	1	0.626	1.16	0.65	2.07
SES	-0.20	.05	14.90	1	<.001	0.82	0.74	0.91
Single Words	-.08	0.36	.05	1	0.820	0.92	0.46	1.85
Phrases	0.36	0.36	1.01	1	0.314	1.44	0.71	2.91
Constant	-2.93	1.21	5.85	1	.016	0.05	-	-

Life Skills Training. A logistic regression indicated that child's age, W-ADL total score, and EDI dysphoria *t*-scores were significantly associated with the likelihood that caregivers reported an unmet service need in life skills training, while EDI reactivity *t*-scores, language level, SES, and ethnicity were not significant predictors ($n = 375$). There were three standardized residuals with values above 2.5 standard deviations, which were kept in the analysis. The model explained 18.7% (Nagelkerke R^2) of the variance in unmet service needs and correctly classified 64.3% of cases ($\chi^2(8) = 56.20$, $p < .001$). Every one unit increase in child's age was associated with 1.13 times increase in the odds of needing life skills training, controlling for all other variables in the model (*B* = .12, $p < .001$). Increasing W-ADL scores were associated with a reduction in the likelihood of needing life skills training (*B* = .05, $p = .018$). For each one unit increase in EDI dysphoria *t*-scores, there was a 1.08 increase in the odds of needing life skills training ($B = .07, p < .001$; Table 9).

Table 9

Logistic Regression Predicting the Likelihood of Unmet Life Skills Training

							95.0% CI for Odds Ratio	
	B	SE	Wald	*df*	*p*	Odds Ratio	Lower Bound	Upper Bound
Age	0.12	.02	24.96	1	<.001	1.13	1.08	1.18
W-ADL	-.05	.02	5.64	1	.018	0.95	0.92	0.99
EDI Dysphoria	.07	.02	21.03	1	<.001	1.08	1.04	1.11
EDI Reactivity	-.00	.02	0.07	1	0.799	1.00	0.97	1.03
Ethnicity	-.02	.29	0.01	1	0.940	0.98	0.55	1.74
SES	-.09	.05	3.74	1	0.053	0.91	0.83	1.00
Single Words	-.56	0.33	2.93	1	0.087	0.57	0.30	1.084
Phrases	-.43	0.33	1.65	1	0.199	0.65	0.34	1.25
Constant	-4.05	1.15	12.36	1	<.001	0.02	-	-

Occupational Therapy. A logistic regression indicated that child's age and EDI dysphoria *t*-scores were significantly associated with the likelihood that caregivers reported an unmet service need in occupational therapy, controlling for all other variables in the model ($n = 318$). There were six standardized residuals with values above 2.5 standard deviations, which were kept in the analysis. The model explained 26.8% (Nagelkerke R^2) of the variance in unmet service needs and correctly classified 73.0% of cases ($\chi^2(8) = 68.97, p < .001$). Every one unit increase in child's age was associated with 1.22 times increase in the odds of needing occupational therapy, controlling for all other variables in the model ($B = 0.20, p < .001$). For each one unit increase in EDI dysphoria *t*-scores, there was a 1.06 increase in the odds of needing occupational therapy ($B = .06, p = .002$). Increasing SES was associated with a 0.87 decrease in the likelihood of needing occupational therapy services ($B = -.15, p = .012$; Table 10).

Table 10

Logistic Regression Predicting the Likelihood of Unmet Occupational Therapy Needs

							95.0% CI for Odds Ratio	
	B	SE	Wald	*df*	*p*	Odds Ratio	Lower Bound	Upper Bound
Age	0.20	.03	35.00	1	<.001	1.22	1.11	1.31
W-ADL	.02	.02	1.01	1	.314	1.02	0.98	1.07
EDI Dysphoria	.06	.02	9.72	1	.002	1.06	1.02	1.10
EDI Reactivity	-.02	.02	0.76	1	0.383	0.99	0.95	1.02
Ethnicity	-0.24	0.33	0.52	1	0.473	0.79	0.42	1.50
SES	-0.15	.06	6.33	1	.012	0.87	0.77	1.00
Single Words	-0.46	0.38	1.50	1	0.220	0.63	0.30	1.32
Phrases	0.41	0.39	1.10	1	0.294	1.51	0.70	3.24
Constant	-4.71	1.37	11.84	1	<.001	.01	-	-

Behavioral Support. A logistic regression indicated that EDI dysphoria *t*-scores and SES were significantly associated with the likelihood that caregivers reported an unmet service need in behavioral support services, controlling for all other variables in the model ($n = 346$). No outliers were identified. The model explained 10.1% (Nagelkerke R^2) of the variance in unmet service needs and correctly classified 64.2% of cases ($\chi^2(8) = 27.06, p < .001$). For each one unit increase in EDI dysphoria *t*- scores, there was a 1.04 increase in the odds of needing behavioral support services ($B = .04, p = .006$). Increasing SES was associated with a .84 decrease in the likelihood of needing behavioral support services ($B = -0.18, p = .012$; Table 11).

Table 11

Logistic Regression Predicting the Likelihood of Unmet Behavioral Support Needs

	B	SE	Wald	*df*	*p*	Odds Ratio	95.0% CI for Odds Ratio Lower Bound	 Upper Bound
Age	.04	.02	3.30	1	.069	1.04	1.00	1.08
W-ADL	.00	.02	0.00	1	0.952	1.00	0.96	1.04
EDI Dysphoria	.04	.02	7.49	1	.006	1.04	1.01	1.08
EDI Reactivity	-.011	.02	0.53	1	0.466	0.99	0.96	1.02
Ethnicity	0.19	0.30	0.41	1	0.521	1.21	0.68	2.17
SES	-0.18	.05	13.57	1	<.001	0.84	0.76	0.92
Single Words	-0.15	0.32	0.22	1	0.640	0.86	0.46	1.61
Phrases	0.02	0.33	0.01	1	0.946	1.02	0.54	1.95
Constant	-1.37	1.10	1.54	1	0.215	0.26	-	-

Main Findings: Qualitative Results

The rapid qualitative analyses revealed 10 themes within the three primary domains in the interview guide: unmet service needs, barriers to service access, and treatment priorities for individuals with profound autism. Within the *unmet service needs* domain, participants described a pervasive lack of services for profound autism, the need for services that promote social and community integration, and the need for specialized healthcare providers, respite care, case-management, and services that support caregivers both practically and emotionally. Within the *barriers to service access* domain, caregivers emphasized the persistent shortage of service providers with knowledge of profound autism who are accessible and affordable, the limitations of one-size-fits-all service models, and the repeated exclusion from services due to behaviors (e.g., severe challenging behaviors) or low independent functioning (e.g., inability to toilet independently). Finally, in the *treatment priorities* domain, participants identified their desire for centralized support services that provide integrated care from multiple providers in cohesive treatment settings, along with a desire for livable community settings that promote overall happiness and wellbeing for adults with profound autism (Table 12).

Table 12

Caregiver Quotations Illustrating Themes

Domains and Themes	Participant Quotations
Unmet Service Needs	
Social and community integration	"I just want her to be included. She's always off to the side. I would like her to have the skill to be more included in conversations." (326: Mother, 15-year-old, White, Asian, Latina female with profound autism, CA)
Specialized healthcare providers	"And just the diagnosis in general, I feel like it's too broad for what she needs. I think she needs more specialized services. Even the doctors, it's very difficult to find healthcare that understands her needs because autism is just too broad." (310: Mother, 14-year-old, White, Latina female with profound autism, FL)
"Just people to be able to come and care for your kids"	"We tried to hire people who are familiar with her because she's so severe. But now because of the pay - it's low. I mean, it's $15.25 an hour now. And it's part time. And her behaviors are very severe. So it's hard to just find anybody that would come and do this." (381: Mother, 16-year-old, White, Middle Eastern female with profound autism, MI)
Case management	"It remains very challenging to even figure out what your options might be, and then unnecessarily additionally challenging to figure out how to actually access them and maintain using them." (284: Mother, 23-year-old, White male with profound autism, NJ)
Support for caregivers	"I don't even know what that looks like anymore" (269: Mother, 12-year-old, White, Latino male twins with profound autism, AZ); "I always question everything. Yeah. So just having somebody that I can ask. So that's where BCBA would come in, and I can ask these questions." (310)
Barriers to Service Access	
Accessibility and SES	"Services in the community are few and far between and the people who are prepared to work with her are also somewhat few and far between" (97: Mother, 13-year-old, White female with profound autism, CA); "The home district couldn't offer me anything. I'm sure I could have gone for another district, but we are, as I said, low income. I do not have a vehicle" (250: Mother, 12-year-old, White male with profound autism, MI).

One-size-fits-all service models	“And I feel like right now it’s very much - everything has to fit. So whatever they offer you, it’s a one size fit. So it’s supposed to fit your child one way. And then it’s probably not geared for his exact needs” (554: Mother, 12-year-old, Latino male with profound autism, CA)
Systemic exclusion from services	“It just seems like anytime I felt like I found something, there was always something else that was like, ‘Oh nope. Not your kid’” (326).
Treatment Priorities	
Centralized services with integrated care	[a place that] “will actually support him physically, emotionally, and try to understand his language and help others understand it too” (110: Mother, 14-year-old, African American male with profound autism, NC).
Happy, healthy, safe	“I just hope that they’re happy, I mean, whatever that looks like. I hope nobody takes advantage of them. I hope nobody hurts them” (269)

Unmet Service Needs

Overall, caregivers expressed a myriad of unmet service needs. As one caregiver summarized: “There is no help. Doctors don’t want to help. Agencies don’t want to help. There is no help” (P269). Within the domain of unmet service needs, the following themes emerged:

Services that promote social and community integration. Qualitative analyses converged with the finding that many caregivers are seeking more socialization opportunities for their adolescents and adults with profound autism. When asked about the types of services that their children need but are not currently receiving, most caregivers described services designed to promote social interaction, social communication, and community integration (participant IDs follow quotations). Some caregivers described the importance of integrating social clubs for connectedness with concrete training to develop social communication skills (either verbally, nonverbally, or both): “I just want her to be included. She’s always off to the side. I would like her to have the skill to be more included in conversations” (326). Some caregivers envisioned adaptations to social clubs for individuals who communicate using AAC devices to practice using these devices in social settings. In the quantitative analyses, social clubs or activity groups were a higher priority for caregivers of individuals who spoke in phrases/ sentences or single words relative to caregivers of children with no words. Qualitative reports expanded this finding by highlighting the ways that these groups could be adapted to accommodate a range of language levels.

Furthermore, caregivers expressed a need for services that promote other skills related to community integration, including adaptive daily living skills (e.g., life skills, safety skills, caring for self, feeding, cooking, hygiene, toileting independently), friendship development, functional communication training, and basic job skills. In the quantitative data, the ability to indicate when hurt or sick was a priority treatment target for caregivers; qualitative data complemented this finding by highlighting the importance of services designed to promote communication of fundamental wants and needs. Caregivers emphasized that they have limited options for ABA or other behavioral services to develop these skills and that many agencies have very long waiting lists. They discussed the importance of parent training for managing challenging behaviors, developing coping skills, and addressing sensory interests or aversions that may inhibit community integration.

Specialized healthcare providers. Qualitative reports converged and expanded upon the finding that caregivers of individuals with profound autism report a need for health care providers with autism-specific training. Caregivers consistently described the challenges of identifying medical professionals who are willing and capable of working with individuals with profound autism. They discussed long waitlists for specialized healthcare providers, providers who minimize symptoms (e.g., gastrointestinal issues) as autism-related without grasping complex differential diagnoses, and a lack of knowledge regarding self-injurious behaviors. One caregiver expressed that the heterogeneity of the autism spectrum may contribute to the lack of trained healthcare providers:

> "And just the diagnosis in general, I feel like it's too broad for what she needs. I think she needs more specialized services. Even the doctors, it's very difficult to find healthcare that understands her needs because autism is just too broad" (310).

Caregivers are seeking more doctors and psychiatrists who are knowledgeable about treating severe behaviors medically, behaviorally, and pharmacologically.

"Just people to be able to come and care for your kids" (110). Qualitative findings revealed the urgent priority to increase access to respite care to improve support for caregivers and families. Caregivers repeatedly highlighted the lack of professionals with autism-specific knowledge and training to respond to a range of behaviors, de-escalate challenging behaviors, understand communication attempts, support daily needs, and facilitate self-care tasks as needed. Caregivers emphasized that the access to respite care needs to be immediate in the event of emergencies. Single parents or parents with more limited support networks shared that they need respite care to go to their own doctor's appointments or to run errands. One caregiver explained that the absence of support is due to high turnover rates and inadequate training to work with individuals with severe behaviors:

> "We tried to hire people who are familiar with her because she's so severe. But now because of the pay – it's low. I mean, it's $15.25 an hour now. And it's part time. And her behaviors are very severe. So it's hard to just find anybody that would come and do this." (381).

Another caregiver reported that her family is eligible for 600 hours of respite care a year, but they are not receiving any hours due to the aggression of her twins with profound autism, inability to toilet independently, overall severity of their diagnoses, and low respite provider pay (269). Caregivers noted that there are similar issues with high turnover rates and inconsistent providers in group homes or adult rehabilitation settings. In sum, many families reported that they have received very few (if any) respite hours over the past five years.

Case management and service identification. Qualitative reports converged with quantitative findings that improved access to case management is necessary to help caregivers identify and obtain proper services. According to one caregiver, "I don't even know where to look" for services (381). Another caregiver described the lack of service directories or support for service identification:

> "It remains very challenging to even figure out what your options might be, and then unnecessarily additionally challenging to figure out how to actually access them and maintain using them (284).

For example, caregivers explained their confusion about working with behavior analysts in the adult service world and navigating their convoluted payment systems. Caregivers often act as case managers for their loved ones with little support from schools or local agencies. One caregiver explained:

> "As the parent you're expected to get to know all of those systems and then to navigate them with very little assistance. And so that part is really difficult" (483).

Overall, caregivers conveyed a lack of support at all stages of service identification and maintenance for adolescents and adults with profound autism. Unfortunately, these challenges may be exacerbated by schools and other service delivery systems that "fight you every step of the way" in the process of obtaining appropriate services (577).

Support for caregivers. Qualitative analyses suggested that caregivers of adolescents and adults with profound autism are so focused on their child's needs that they have difficulty envisioning services to support themselves. When asked about her support needs, one caregiver responded, "I don't even know what that looks like anymore" (269). Caregivers emphasized the importance of services that relieve their moment-to-moment care responsibilities and reiterated the need for respite care and treatment coordination. Some caregivers requested solution-oriented support groups designed for families, parents, and siblings living with profound autism. They noted that existing support groups cater to individuals with fewer support needs or parents of younger children on the autism spectrum. Furthermore, caregivers would appreciate greater transparency in the service delivery system, a designated point person to address when questions arise, and a liaison between parents and group homes and other adult programs. In the absence of these supports, parents shared that they feel alone with their questions. As one caregiver shared, "I always question everything. Yeah. So just having somebody that I can ask. So that's where BCBA would come in, and I can ask these questions." Many caregivers expressed feeling overwhelmed by the absence of support to navigate severe, challenging behaviors in crises. Thus, caregivers would benefit from parent training services and access to responsive, wraparound support.

Barriers to Service Access

Services are few and far between: Accessibility and SES. Qualitative analyses converged and expanded upon quantitative findings related to barriers to service access. Caregivers consistently referenced the shortage of local services or community spaces for individuals with profound autism and their families. As described by one caregiver:

> "Services in the community are few and far between and the people who are prepared to work with her are also somewhat few and far between" (97).

Some families reported the need to travel (sometimes 1-2 hours) to access appropriate services for their child. Navigating travel to school and additional therapies may pose a burden for caregivers: "And it was a lot to be at– two-hour drive, at school for seven hours, two hours home and then go to speech for another hour. Like, really?" (326).

Caregivers described variations in state-specific services (e.g., Regional Centers are specific to California) and insurance benefits available to support their families. They reported the challenges of working with insurance companies to seek coverage for necessary services for their child. As one caregiver shared, “I feel that he could use feeding therapy, but that’s not covered by insurance, and I don’t have that kind of money” (250). When the cost of private therapies is prohibitive, caregivers may turn to their school district for additional support during adolescence. However, some caregivers reported that their school districts do not provide the full range of necessary services: “The home district couldn’t offer me anything. I’m sure I could have gone for another district, but we are, as I said, low income. I do not have a vehicle” (250). One caregiver described her bus journeys with her son to access ABA services over the course of five years with frequent turnover in behavioral technicians, averaging 10 different technicians each year. Eventually, services dropped the family with complaints that they were missing too many sessions, highlighting the challenges of sustaining support when service access is dependent on having a vehicle.

One-size-fits-all service models. Qualitative analyses converged with the quantitative finding that many caregivers experience a shortage of specialized service providers. Caregivers elaborated on this finding in the qualitative data by highlighting the lack of personalized care as a key barrier to service access. According to one caregiver, “I guess what I see is a lack of individualized services” (77). Another elaborated:

> “And I feel like right now it’s very much – everything has to fit. So whatever they offer you, it’s a one size fit. So it’s supposed to fit your child one way. And then it’s probably not geared for his exact needs” (554).

Caregivers shared that services rarely adapt to the needs of each client to develop new skills. As a result, services are unlikely to promote progress towards individualized treatment goals. One caregiver expressed frustration with the lack of stimulation at her son's adult rehabilitation program, describing that he is often engaged in passive activities. Another added, "Finding the right program that suited her was, I think, the most challenging" (408). Caregivers explained that schools and local services are ill equipped to customize treatment strategies to teach priority skills, such as essential self-care tasks that would promote independence and might increase the likelihood of inclusion in other services (e.g., bathing, washing hands, toileting).

Systematic exclusion from services. The repeated exclusion from services due to specific behaviors or traits was another theme that emerged in relation to barriers to service access. As one parent stated, "It just seems like anytime I felt like I found something, there was always something else that was like, 'Oh nope. Not your kid'" (326). Qualitative reports indicated that a child's behavior problems are a frequent barrier to service access. One caregiver shared that it is impossible to find service providers who are willing to work with the follow behaviors:

> "She hits herself. She is trying to communicate with you constantly, but you have to understand her to understand what she wants. So, she bangs her head on the wall. She puts holes in the wall" (381).

Another parent noted that her child's behaviors are severe and unpredictable. As a result, her family has "pretty much exhausted every ABA service where we live" (310). Furthermore, caregivers expressed that ABA services screen and reject families based on the severity of behaviors because their children are liabilities. Caregivers experience "unbelievable waiting lists" for more intensive, wraparound services such as severe behavior units (310). During the summer, caregivers struggle to identify programs that accept children with significant behavioral challenges: "You know there's no accessible summer camps for a child who has behavioral challenges? Zero" (554). Regarding group homes, one legal guardian shared that 25 group homes excluded her sister before they found one that was willing to work with her behavioral and mental health challenges (490).

Furthermore, caregivers noted that it is difficult to identify services for their children during transition phases (such as becoming a teenager or entering adulthood). Some caregivers reported an increase in aggression and the unpredictability of behaviors during these transition phases, contributing to exclusion from services. Caregivers indicated that severe and challenging behaviors may negatively influence the quality of educational services in school settings. When schools are unprepared to manage challenging behaviors in the classroom setting, students may experience early dismissals, suspensions, or frequent reshuffling to different classrooms. As one caregiver described: “She ended up not even finishing the year in these schools because they didn’t want to deal with the kids that were severe like X, so with severe behaviors” (310).

Finally, caregivers shared that deficits in adaptive functioning may serve as another roadblock to service access. Caregivers expressed concerns about trusting their children to the care of other adults to handle bathing, toileting, and other vulnerable self-care tasks. Simultaneously, service providers may exclude adolescents or adults who are unable to toilet independently. Thus, individuals are unable to access services that could increase their adaptive functioning or reduce challenging behaviors because they demonstrate the very behaviors that these services may improve: self-injurious behaviors, severe externalizing behaviors, unpredictable behaviors, or low adaptive daily living skills.

Treatment Priorities

Centralized services with integrated care. Qualitative results expanded findings related to priority treatment targets by providing a comprehensive perspective on the types of treatment settings that families deem most useful. Caregivers frequently reiterated their desire for care centers that integrate multiple services into one cohesive setting. They described a need for individualized day programs with varied providers to work with each person throughout the day. This ideal service setting would include speech therapists, occupational therapists, behavioral therapists, a sensory room, and a quiet break room. As one caregiver described:

> "Ideal service would be he would go to his dayhab, and there would be, again, the right therapist, and the speech therapist. There would be one-to-one attention with meaningful, constructive activities" (608).

Caregivers hope that these service settings would provide individualized interventions throughout the day to teach skills relating to communication, self-care, socialization, and life skills. They seek care settings that provide opportunities for greater autonomy with an array of meaningful activities. Caregivers also emphasized the importance of services that encourage physical and emotional wellbeing. For instance, one caregiver stated that she hopes to find a place that "will actually support him physically, emotionally, and try to understand his language and help others understand it too" (110). For providers to understand the language of someone who is nonspeaking or minimally verbal, they need to have the capacity to get to know their clients and to appreciate different communication styles. They need adequate resources to recognize each person's interests, preferences, and desires. In contrast, caregivers expressed that services punt them from one location to another and that providers do not have the bandwidth to tailor treatment to each client. Thus, caregivers envision centralized treatment centers with case managers to supervise the teams of therapists and to connect families to resources, along with a 24/7 nurse line to support caregivers with problem solving in crisis situations.

Happy, healthy, and safe. Caregivers expressed uncertainty about the future and a desire for settings that will engage and nourish adults with profound autism. They indicated that they want to create spaces that are accepting and support ongoing learning and development. One mother summarized that she wants her son to live in a home that "feels like a home, where he is accepted for who he is" and where therapies (OT, speech therapy) are always accessible (554). Another caregiver underscored the importance of affordability: "[I'm hoping for a] community setting for her to live independently with supports in hand that was affordable" (326). The settings described by caregivers ranged from group homes to communities with multiple houses for adults with disabilities. Above all, caregivers emphasized that they want their children to be happy. They described safe community homes that "bring a little bit of joy." One caregiver of twins with profound autism summarized:

> "I just hope that they're happy, I mean, whatever that looks like. I hope nobody takes advantage of them. I hope nobody hurts them" (269).

In the absence of sufficient supports for accessing services or future planning, many caregivers expressed concern about what would happen to their children as they age. They conveyed a sense of urgency for the development of programs that will support their children throughout adulthood.

Discussion

This mixed-methods study is among the first to conduct a needs assessment focused expressly on adolescents and adults with profound autism, a population that is critically underrepresented in the autism research literature (Russell et al., 2019; Siegel, 2018). Expanding upon prior findings that adults on the autism spectrum experience unmet service needs (e.g., Shattuck et al., 2020), this study explored the nature and contributing factors of these unmet service needs for individuals with profound autism and their families. Qualitative findings converged and expanded findings in the quantitative data regarding patterns of caregiver-reported unmet service needs, barriers to service access, and priorities for improving care delivery systems. These findings provide critical information regarding the state of treatment services for profound autism and provide both challenges and possible solutions to inform future treatment research objectives (Powell et al., 2017).

Unmet Service Needs

Themes emerging from the qualitative data within the category of unmet service needs indicated a pervasive lack of services for profound autism. Specifically, caregivers voiced a need for services that promote social and community integration, along with specialized healthcare providers, respite care, case-management, and support for navigating complicated service systems. Quantitative analyses revealed priority service needs in the domains of regular socialization activities, primary health care services with autism-specific training, social skills instruction, life skills instruction, occupational therapy, and behavioral support. The least commonly endorsed service needs were mental health counseling and sexual health education in both quantitative and qualitative data, perhaps signifying that these services are lower priorities for individuals with profound autism.

Lower socioeconomic status significantly predicted a greater number of total unmet service needs. Additionally, lower SES increased the likelihood that caregivers reported unmet service needs in specific service categories, including social clubs/ activity groups, primary health care services, social skills training, occupational therapy, and behavioral therapy. This finding is consistent with well-documented reports of disparities in service access for individuals with greater socioeconomic status disadvantage (e.g., Drahota et al., 2020). Themes emerging from qualitative narratives revealed that the quality and quantity of services covered by insurance and the cost of traveling to access appropriate therapies limits service access. Prior research reveals that racial and ethnic minority groups and autistic children from low-income families have less access to acute care, specialized services, educational services, and community services compared to higher-income and White families (Smith et al., 2020). In this investigation, racial and ethnic minority status was not significantly associated with the sum of unmet service needs. This sample may have been underpowered to detect these differences given the disproportionate representation of individuals who identified as White and non-Hispanic.

Next, we explored the effects of demographic and clinical factors (emotion regulation, adaptive daily living skills, language level, SES, age, and ethnicity) on the likelihood of unmet service needs in specific service categories. Caregivers of individuals who spoke in single words or phrases/sentences were more likely to report a need for social clubs or activity groups than caregivers of nonspeaking individuals, suggesting that these types of socialization opportunities constitute a more pressing service need for individuals with some functional language. For nonspeaking individuals, caregivers suggested incorporating concrete skill-building activities or adapting these groups for individuals who communicate using alternative and augmentative communication (AAC) devices to increase opportunities for socialization. Caregivers of older individuals reported a greater need for social skills training programs focused on explicit instruction and skill building than caregivers of younger individuals. This is not surprising given the known decline in evidence-based socialization programs as autistic individuals enter adolescence and adulthood (Mason et al., 2021).

Differences in challenges with emotion regulation (e.g., whether an individual demonstrates more internalizing or externalizing behaviors) influenced the type of socialization programs that families were seeking. While increased emotional reactivity was related to a need for social clubs or activity groups, elevated sadness or unease was associated with a need for social skills training. Caregivers of individuals who present with lower mood may seek structured social skills training to enhance social-emotional functioning and to promote overall wellbeing. On the other hand, caregivers of individuals with behavioral challenges may desire social clubs or activity groups as programs that promote a sense of belonging and meaningful social engagement. Qualitative data suggested that essential services commonly exclude individuals with severe, challenging behaviors.

Quantitative findings shed light on factors related to the need for services that promote fundamental daily living skills. Caregivers of older individuals were more likely to report the need for life skills training and occupational therapy than caregivers of younger individuals. This finding suggests that it is essential to develop programs that promote adaptive daily living skills throughout adolescence and into adulthood. Elevated feelings of sadness and low mood were associated with greater needs for life skills training, occupational therapy, and behavioral therapy. Caregivers may seek services that promote functional skill acquisition for individuals with lower mood because the lack of meaningful skill-building activities contributes to lower emotional wellbeing (Mason et al., 2021; Scheeren et al., 2021; Taylor et al., 2015).

Primary health care services with autism-specific training, respite care, and case management services were key unmet needs for caregivers of individuals with profound autism. Quantitative and qualitative analyses revealed the pressing need for primary health care services with medical staff trained in profound autism. Specifically, caregivers described the significant lack of health care providers with specialized knowledge about profound autism and the unique physical and behavioral health needs of this population. Research suggests that pediatricians rarely discuss transitioning to an adult provider or adult healthcare needs with patients with developmental disabilities (Cheak-Zamora et al., 2013), and this guidance may be even more limited with patients with profound autism.

Qualitative findings underscored the importance of developing services to support caregivers, including respite and case management. It is an urgent priority to increase access to respite care to support caregivers in managing daily tasks, attending to self-care, and caring for other family members with support from a trained adult. There is limited research on effective models of respite care for individuals on the autism spectrum to guide the development of comprehensive respite programs for this population (Cooke et al., 2020). Our findings indicate that these programs should incorporate comprehensive training in managing challenging behaviors to support caregivers. With little support from trained respite providers, parents assume the roles of case managers for their loved ones. During the schooling years, families often receive support from the special education system to organize services, yet this centralized coordination wanes following high school (Elster & Parsi, 2020). Through qualitative narratives, caregivers described challenges identifying potential services and managing care. In the absence of appropriate support to identify treatment services or respite care, many caregivers are isolated in their moment-to-moment care responsibilities and decision-making.

Barriers to Service Access

A shortage of service providers in the area was the most frequently endorsed barrier to service access in the quantitative data, followed by child's behavioral problems, COVID-19 resulting in decline or loss of services, cost of services/insurance does not cover, no service providers in the area, unsatisfied with service providers in the area, scheduling, transportation, or other barriers. Qualitative analyses elucidated key themes relating to these barriers, including the persistent shortage of accessible and affordable service providers with knowledge of profound autism, the limitations of one-size-fits-all service models, and the repeated exclusion from services due to severe challenging behaviors or low independent functioning. Regarding the role of SES, qualitative narratives revealed that the quality and quantity of services covered by insurance and the cost of highly specialized services limits service access. This is consistent with findings that lower SES families have reduced access to specialized services and experience a greater number of structural barriers in their quest to access services (Pickard & Ingersoll, 2016; Smith et al., 2020). The presence of severe, challenging behaviors (e.g., self-harm, aggression) is another factor that limits service access. Qualitative findings align with prior reports that service-providing agencies avert individuals with challenging behaviors because they are unwilling or unable to meet their needs (Anderson & Butt, 2018). Similarly, caregivers reported that service providers are often under-resourced to support adolescents or adults who require more substantial support in daily living tasks (e.g., toileting), which may serve as another barrier to service access. This is consistent with findings that more limited adaptive functioning (Maenner et al., 2013) and greater communication needs (Burke & Heller, 2017) are associated with lower levels of service access or utilization.

Treatment Priorities

Key stakeholders offer valuable guidance towards developing autism treatment priorities (Fletcher-Watson et al., 2019; Pellicano et al., 2014), yet the voices of stakeholders aligned with profound autism have not been explicitly identified in these efforts (Roche et al., 2021). Caregivers indicated the following as urgent treatment targets for adolescents and adults with profound autism: communicating when they are feeling hurt or sick; recognizing emotions and calming down when they are upset; decreasing aggressive or self-harm behaviors; requesting things that they need or want; practicing independent living skills; and increasing verbal communication. These treatment priorities align with unmet needs for social clubs, social skills training, life skills, occupational therapy, and behavioral therapy, as these services may promote emotion regulation, life skills, and functional communication. Self-reporting autistic adults and caregivers have also expressed preferences for research related to immediate needs and life skills (Gotham et al., 2015; Pellicano et al., 2014; Roche et al., 2021).

Thematic analysis of treatment priorities revealed the urgency of coordinating and centralizing treatment services so that families may access personalized medical and clinical supports for the individual with profound autism and the entire family. Caregivers expressed a desire for meaningful day programs that teach functional skills and integrate complementary services (e.g., OT, behavioral therapists) into one cohesive treatment setting. This aligns with other qualitative reports that autism services need to be flexible to meet individual needs, and more comprehensive, continuous, and integrated in order to be most useful (Sosnowy et al., 2018). Additionally, caregivers stressed the importance of increasing supports throughout all stages of adulthood for individuals who require 24/7 access to care. Ageing caregivers expressed concerns about the future and prospects for their children with profound autism in the absence of meaningful social services, group homes, or inclusive communities for people with severe disabilities. They reiterated the hope that their children will be happy, healthy, and safe in the future.

Limitations and Future Directions

This research provides important information on the service landscape and treatment priorities for caregivers of individuals with profound autism. Simultaneously, it important to consider limitations in framing these findings. First, one limitation to sampling in a sequential mixed methods design is that the sample collected in the quantitative methods may limit the diversity of the qualitative sample. While quantitative participants were randomly recruited, it does not necessarily follow that they provide diverse accounts for the purposes of the study

(Palinkas et al., 2015). Specifically, minority groups were underrepresented in the quantitative sample and participants were unevenly distributed across states. Significantly more data is needed to draw comparisons between racial and ethnic groups, state-specific services, and communities (e.g., rural vs. urban) within each state. Although important information is lost when aggregating racial identities in the quantitative data (e.g., collapsing all races other than White), this recoding allowed the inclusion of race in a quantitative model given limited diversity in our sample. Future research will focus on targeted recruitment efforts to investigate treatment access and priorities for racial and ethnic minority groups as well as underserved communities across the U.S. (Broder-Fingert et al., 2020). Future research efforts may also benefit from longitudinal studies to understand trajectories of service access and utilization over time in a range of communities.

To promote diversity of experiences within the qualitative data, interviewees were selected from the quantitative sample by maximum variation sampling, a sampling method that aims to identify both variations and common themes across unique accounts. The sampling criteria selected were variation in state of residence, racial/ethnic diversity, and SES (as captured by income or caregiver educational status reported on the survey). As a result, the qualitative sample includes greater representation of individuals who identify as racial and ethnic minorities (races other than White/ Caucasian = 60%; Hispanic or Latino/a/x = 50%) and report that their total combined family income is less than \$50,000 per year (50% reported income between less than \$14,999 and \$49,000). Greater diversity within the qualitative sample increases the external validity of these findings to capture themes in treatment access and priorities for a range of caregivers living with profound autism.

Regarding the interview sample, the self-selection process for electing to participate in interviews my influence the generalizability of these findings. For instance, these parents may have been motivated due to stronger feelings regarding service systems than parents who did not elect to participate. However, it is important to note that over 70% of quantitative participants expressed interest in completing an interview.

Another limitation is that this study did not include formal assessments to confirm diagnoses of profound autism. Rather, the screening stage of the survey defined "with autism and high support needs" for caregivers to indicate whether their child met criteria for *intellectual delay/ disability, minimal verbal ability, and/or requires substantial support in daily life*. Given the variability in descriptors for individuals with profound autism (e.g., severe autism, more severely impacted, lower functioning) and variable access to comprehensive diagnostic evaluations, autism and high support needs categorized this sample. Within the quantitative sample, most caregivers endorsed co-occurring diagnoses of ID and limited verbal communication (no words at all/single words). In the qualitative sample, all participants required continuous support and access to care. More research is needed to characterize participants with profound autism in relation to their service needs to capture the nuanced experiences of families seeking appropriate treatments. Additionally, an adaptive functioning measure with norm-referenced standard scores may provide greater insight into the relationship between adaptive functioning and service access.

Finally, this study looked specifically at caregiver perceptions of treatment access. It is likely that educators, clinicians, and other service providers would provide novel suggestions for reducing disparities in treatment access and treating individuals with profound autism. Similarly, the perspectives of individuals with profound autism may enhance understanding of important next steps in treatment research for this population. More research is needed to develop strategies to meaningfully engage individuals with ID in priority-setting exercises and to thoughtfully monitor treatment approaches to assess whether they enhance quality of life and wellbeing (Roche et al., 2021).

This investigation has important implications. These findings will increase access to evidence-based services for individuals with profound autism. Results suggest that families would benefit from a line of research that develops treatment strategies for managing challenging behaviors, increasing functional communication, and improving daily living skills. Ideally, these services would coalesce into cohesive, accessible treatment settings with specialized treatment providers trained in individualized, evidence-based strategies. These settings may also offer socialization opportunities and connection for families living with profound autism. Case managers and a resource hotline would help families to secure social benefits (e.g., Supplemental Social Security Income, Medicare) and provide support for families during crises at home. These integrated service settings may offer group homes or other adult living communities that provide meaningful stimulation, safety, and community for ageing adults with profound autism.

Ongoing collaborations with stakeholders will inform the selection of program components, development of intervention methods, and design of implementation strategies (Eldredge et al., 2016; Mani et al., 2013; Powell et al., 2017; Schaafsma et al., 2013). A future mixed methods study on provider perspectives regarding treatment services and quality of care will build on these findings to optimize treatment services. These explorations may reveal the types of organizations and providers that are ideal for care improvement efforts. For instance, transitional programs may be embedded within educational and medical settings to support the transition into adult services for adolescents with profound autism (Cheak-Zamora et al., 2015). Primary care providers with knowledge of profound autism may serve as a liaison to other services (Cheak-Zamora et al., 2021).

Future efforts will also focus on developing evidence-based strategies to work more effectively with individuals with profound autism. It is important to recognize that heterogeneity that exists within the profound autism population and to respond with tailored models of care to fit individual needs. Combining intervention models (e.g., in the context of a Sequential Multiple Assignment Multiple Trial) may hold promise for systematizing a personalized approach to intervention (Kasari et al., 2018). It is likely that comprehensive, flexible approaches will improve quality of life for individuals with profound autism and their families. Furthermore, coordination between care providers and ongoing consultation with stakeholders is critical to tailoring interventions for delivery in community settings and facilitating intervention uptake (Wood et al., 2015).

Conclusion

This investigation revealed service needs, barriers, and treatment priorities for individuals with profound autism. Next steps in this line of research include ongoing needs assessments with community stakeholders, assessment of provider and organizational characteristics for agencies serving this population in communities, and the development and dissemination of EBPs for this population (Aarons et al., 2011). Ultimately, this research aims to improve treatment services that promote overall wellbeing and enhanced quality of life for individuals with profound autism and their families.

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Appendix A

Caregiver-report survey

Thank you for agreeing to complete this survey. Since respondents will be parents/guardians, we refer to the person with autism as “your child.” If you have more than one child on the autism spectrum, please complete this survey with one child’s service needs in mind.

Screening page:

1. Do you and your child live in the United States?
    1. Yes/ No
2. Are you 18 years or older?
3. Are you reporting on a child who is aged 12 years or older?
    1. Yes/No
4. Does your child have a diagnosis of Autism Spectrum Disorder/ Autistic Disorder made by a professional?
    1. Yes/No
5. Does your child have High Support Needs? High Support Needs: Your child has an Intellectual Delay/ Disability, minimal verbal ability, and/ or requires substantial support in daily life.
    1. Yes/ No

Main Survey:
Caregiver demographics

6. Please identify yourself
    1. Mother
    2. Father
    3. Other (please specify):
7. Are you the legal guardian of your child with autism? Yes, No, Not Sure
8. What is your state of residence?
9. Which of these categories best describes your total combined family income for the past 12 months?
    1. Less than $14,999
    2. $15,000 through $24,999
    3. $25,000 through $49,999
    4. $75,000 through $99,999
    5. $100,000 through $124,999
    6. $125,000 through $149,999
    7. $150,000 through $174,999
    8. $175,000 through $199,999
    9. $200,000 and greater
    10. Don't know

10. What is your highest educational degree?
    1. Less than high school
    2. High school graduate
    3. Some college
    4. Associate’s degree
    5. Bachelor’s degree
    6. Master’s degree
    7. Doctoral or Professional Degree
    8. Other: ___
11. How do you pay for your child’s health care services? (check all that apply_
    1. Private health insurance
    2. Medicaid, State, or Federal insurance program
    3. Self-Pay/Out-of-pocket
    4. My child doesn’t receive health care services
    5. Other: _____

Autistic Adolescent/Adult Characteristics

12. What is your child’s sex assigned at birth?
    1. Male
    2. Female
    3. Intersex
13. What is your child’s gender?
    1. Male
    2. Female
    3. Transgender
    4. Gender variant/ nonconforming
    5. Other
14. How old is your child?
15. What is your child’s ethnicity?
    1. Hispanic or Latino/a
    2. Not Hispanic or Latino/a
16. What is your child’s race? (*check all that apply*)
    1. Asian or Asian American
    2. Black or African American
    3. Middle Eastern
    4. Native American, American Indian, or Alaska Native
    5. Native Hawaiian or Pacific Islander
    6. White or Caucasian
    7. Other (please specify):
17. What type of professional first diagnosed your child with autism spectrum disorder (ASD)?
    1. Developmental pediatrician
    2. Educational team (IEP or EI)
    3. Neurologist

    4. Family doctor/ Pediatrician
    5. Psychologist
    6. None
    7. Other:

18. How old was your child when they were diagnosed with ASD? [fill in age]
19. What type of professional first diagnosed your child with global developmental delay/ intellectual disability/ disorders of intellectual development?
    1. Developmental pediatrician
    2. Educational team (IEP or EI)
    3. Neurologist
    4. Family doctor/ Pediatrician
    5. Psychologist
    6. None
    7. Other:
20. How old was your child when they were diagnosed with Developmental/Intellectual Delays or Intellectual Disability? [fill in age]
21. How does your child typically communicate with you?
    1. No words at all
    2. Usually speaks in single words (1-10 words)
    3. Usually speaks in single words (11 or more words)
    4. Usually speaks in short phrases (2-3 words together)
    5. Usually speaks in full sentences
22. Does your child **currently** have any of the following diagnoses? Check all that apply
    1. Seizures/ Seizure Disorder/ Epilepsy
    2. Intellectual Disability/ Disorders of Intellectual Development
    3. Genetic Disorder
    4. Hearing or Visual Impairment
    5. Attention Deficit/ Hyperactivity Disorder (ADHD)
    6. Mood Disorder (depression, anxiety disorder)
    7. Trauma and Stressor-Related Disorder
    8. Other: _____
    9. None
23. What is your child's current living situation?
    1. With parent(s)/ caregiver(s) in family home
    2. In a residential facility/ group home
    3. Lives on own with support
    4. Lives on own without support
    5. Lives with roommate or spouse
    6. Other: ____
24. Is your child currently employed? (Yes/ No, if yes, branching logic)
    1. Part-time
    2. Full-time
    3. Day program that includes work or vocational activities

25. My child is:
    1. Seeking employment
    2. Not seeking employment

Unmet Service Needs

Please tell us about your child's current specialty service needs

My child is receiving/ My child is not receiving, but needs/ My child is not receiving, and does not need

- Mental Health Counseling (individual therapy, group therapy)
- Sexual Health Education
- Social Skills Training
- Social Clubs/ Activity Groups
- Speech and Language Therapy
- Occupational Therapy
- Physical Therapy
- Life Skills Training
- Behavioral Support
- Vocational/ Job Training or supported employment
- Case Management to find, plan, and coordinate your child's services
- Primary Care Doctor with autism-specific training
- Other: ____
- None

26. For my child is not receiving, but needs, did your child receive some of all of these services in the past (when they were younger)?
    1. Yes
    2. No

27. What barriers do you face in accessing these services? (select all that apply)

- Transportation
- Scheduling
- Child's behavior problems
- Shortage of service providers in the area
- No service providers in the area
- Unsatisfied with service providers in the area
- Cost of services/ my insurance doesn't cover
- COVID-19 disrupted my child's services (decline or loss in services)
- Other: _____
- None

Treatment Priorities

28. *We're interested in identifying skills that are most important to you and your family in order to develop better services for adolescents and adults with autism and high support needs. To help us design better services, we are asking you to rate the importance of your child receiving support to improve each skill below, regardless of whether your child currently uses the skill or not.*

We used the same response scale as Pellicano et al.: 1 = not important at all, 2 = of little importance, 3 = moderately important, 4 = important, and 5 = very important (Gotham et al., 2015)

- Practicing social skills (greetings/ goodbyes, eye-contact, etc.)
- Increasing verbal communication (asking questions, responding to questions, etc.)
- Training in using Augmentative and Alternative Communication devices
- Developing and maintaining friendships
- Recognizing emotions and calming down when they are upset
- Decreasing aggressive or self-injurious behaviors
- Finding and maintaining a job
- Requesting things that they need or want
- Indicating when they are hurt or sick
- Practicing independent living skills
- Developing skills for romantic relationships/ dating
- Increasing physical activity/ exercise

Characterization Measures

- Emotion Dysregulation Inventory (EDI; Mazefsky, Day, et al., 2018; Mazefsky, Yu, et al., 2018): an informant report measure of emotion dysregulation, or emotional distress and problems with emotion regulation.
- Waisman-Activities of Daily Living (W-ADL): measures the level of independence in activities of daily living in adolescents and adults with intellectual and developmental disabilities (Maenner et al., 2013).

Appendix B

Thank you for meeting with me today. As I've mentioned, we want to improve therapies and services available to adolescents and adults with autism and high support needs. Today, I want to learn more about your experiences accessing appropriate services for your child and about the types of services that you feel your child needs. Your input is critical, as you are the expert on this important topic. I'm looking forward to hearing about your experiences.

1. Tell me about your experiences getting help for XX.
   a. *Follow-up:* What challenges have you faced in getting help for XX?
   b. *Follow-up:* What type of service, if any, has been most useful or effective for your child?
2. What comes to mind when you think about services, programs, or activities in your community to support XX?
3. What types of services does XX need that they are not currently receiving?
   a. *If needing more services,* what assistance do you need to help your child access more effective services?
   b. *Follow-up:* Has XX experienced a decline or loss in services as they have gotten older?
   c. *Optional follow-up:* Has XX experienced a decline or loss in services due to COVID-19?
4. *If emotion regulation is a concern:* What strategies, if any, have been helpful for teaching XX how to manage their emotions and behaviors?
5. What are the top skills that you hope XX learns in the coming years?
6. What types of supports do you need as a parent/ caregiver?
7. Let's think about a person working with XX. What would you want them to know about teaching your child new skills?
   a. *Follow-up:* In what type of setting does your child learn best?
   b. *Optional follow-up:* What type of person works best with your child in terms of their personality and skills that they have?
8. Imagine that you could create your ideal support service for your child. What would it be and why?
   a. *Optional follow-up*: What experiences would XX gain from your ideal service?
   b. *Follow-up:* What is essential to make this service successful?
9. What hopes or dreams do you have for XX's future?
10. Is there anything else that you would like to add?