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Exploring the Involvement of Autistic Youth in Decision-Making About Services

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Abstract

Although services are critical for many transition-aged youth, it is unclear the extent to which autistic youth participate in decisions about their services. By exploring the perceptions of autistic youth about their role in services, interventions can be developed to improve their participation. In this study, we interviewed 43 transition-aged youth with autism to explore their involvement in decisions about services. Most youth reported not being involved in decision-making about the types and modalities of disability services. When youth were involved in decisions, the services were often related to education. While youth reported that their parents typically spearheaded decisions about services, youth also reported that their parents often listened to their input. Implications for research, policy, and practice are discussed.

Exploring the Involvement of Autistic Youth in Decision-Making About Services

For young adults with autism, services are often critical to improving outcomes. Services may include a job coach, a personal support worker, financial assistance, tutoring, and therapy. When young adults with autism receive appropriate services, they demonstrate improved outcomes in relation to employment and post-secondary education (Shattuck et al., 2012). However, when they do not receive appropriate services, autistic youth may demonstrate poor post-school outcomes in relation to community living (Myers et al., 2015), employment (Alverson & Yamamoto, 2017), or post-secondary education (Migliore et al., 2012).

When making decisions about services, it is critical to include the perspective of the autistic youth. Indeed, self-determination is a best practice among students with autism (Wehmeyer & Shogren, 2016). When youth are self-determined, they demonstrate improved school (Shogren et al., 2012) and post-school outcomes (Shogren & Ward, 2018). Further, when youth are involved in decisions about services, there are improved outcomes. For example, when youth are involved in individualized education program (IEP) meetings, there are improved academic achievement outcomes (Barnard-Brak & Lechtenberger, 2010). Policy supports youth to be the primary drivers of decision-making. Regarding school services, the Individuals with Disabilities Education Act (IDEA, 2004) encourages youth to spearhead transition planning. Further, adult services (e.g., Medicaid waivers) often focus on having person-centered planning so the individual can have services which meet their particular needs.

Unfortunately, compared to their peers with other types of disabilities and peers without disabilities, youth with autism often demonstrate less self-determination (Shogren et al., 2018). Further, little research has specifically examined youth involvement in relation to decisions about disability services. Given the importance of services for youth with autism, it is critical to

explore their lived experiences in relation to decision-making. By characterizing the involvement of young adults with autism in decisions about services, barriers to involvement can be targeted for intervention and facilitators to involvement can be maximized. To this end, the purpose of this study was to explore the perspectives of young adults with autism in relation to decision-making about services.

At the most basic level, it is important to characterize youth involvement in choosing disability services. In a national survey of youth involvement in IEP meetings, Sanderson and Goldman (2022) found that 28% of youth did not participate at all in IEP meetings. Even with such low participation in IEP meetings, youth involvement may be at its peak during school (versus adult services). Consider the Medicaid Home and Community-Based Services (HCBS) waiver. Less than 20% of youth and their families direct their own waiver services (Friedman, 2018). Upon closer examination of specific services, youth and family direction are more common with respect to educational services, family training, individual goods and services, financial support, and respite. Unfortunately, Friedman was not able to disaggregate the data to characterize the involvement of youth (versus family) involvement. Thus, it may be that youth involvement is less than 20% and varies in relation to the type of service. To ensure that the youth is informing service-related decisions, it is important to understand the extent to which youth (versus their families) may choose their own services. By exploring whether there is a pattern in relation to youth involvement and the type of service, practitioners may be able to target certain services prone to low youth participation.

It is also important to explore youth involvement in choosing the modality of the service. With the COVID-19 pandemic and during its aftermath, many services are being offered in-person and via telehealth (White et al., 2021). Among children with autism, at the beginning of

COVID-19, approximately 40% of parents declined to receive services for their children via telehealth (Aranki et al., 2022). As a result, many children went without needed services. It is unclear the extent to which youth were involved in decisions about the modalities (i.e., in-person or telehealth) of their services. From the broader literature, it seems that there may be tradeoffs with telehealth. For example, telehealth may increase the accessibility of services to youth and families who live in rural areas or have limited access to transportation (Ellison et. al, 2021). Alternatively, telehealth may be inaccessible for some autistic youth due to logistical and sensory-related barriers (Valdez et al., 2021). By eliciting feedback from youth with autism to understand their involvement in choosing service modalities, we can ensure that the modality of the service is accessible and preferable to autistic youth.

In addition, it is critical to explore the role of the family in encouraging or discouraging youth involvement in choosing services. Self-determination is a trait that all individuals have—regardless of the extent of their support needs (Abery & Stancliffe, 2003; Shogren et al., 2015). Yet, the service delivery system is complex, fragmented, and difficult to navigate (Hanley-Maxwell et al., 1995). Because of the complicated nature of disability services, families may be more inclined to make service-related decisions without consulting their son/daughter (Kim & Turnbull, 2004). By exploring the perspectives of autistic youth about family involvement, we can better discern whether such involvement encourages youth self-determination or restricts the youth's role in decision-making.

Finally, it is important to characterize who is most involved in decisions about services. Autistic individuals with co-occurring intellectual disability (ID) often demonstrate less independence than those without ID (Eaves & Ho, 2008). It may be that youth with (versus without) ID also demonstrate less independence in choosing services. Gender may also matter in

decision-making. Female autistic youth may be more likely than males to camouflage (i.e., use strategies to adapt within a non-autistic setting; Cook et al., 2021). Correspondingly, in comparison to autistic males, autistic females may be less likely to discuss services as they may mask their needs. In addition, involvement in decisions about services may relate to location as there are many differences in service delivery systems across states. With different service landscapes, it may be that youth in states with more readily available and individualized services are afforded more opportunities for decision-making.

Given the importance of self-determination among autistic youth, it is essential for them to be involved in decisions related to their own services. In this study, we conducted interviews with 43 youth with autism. In alignment with an emergent design (Patton, 2002), we identified our research questions after data collection. Specifically, after familiarizing ourselves with our data, we formulated the following research questions for this study: Among transition-aged autistic youth, (1) What is their involvement in deciding which services to receive?; (2) What is their involvement in choosing the modality of the service?; and (3) To what extent does their family support or include their involvement in choosing services? Finally, we explored potential patterns among youth involvement in relation to the presence (or absence) of ID, gender and state of residence of the participant.

Method

Design

This study uses data collected as part of a randomized controlled trial to test the effectiveness of a services advocacy intervention for parents. Parents were the primary respondents in the larger study. To be eligible, parents were required to: (a) have a youth aged 16-26 with an autism diagnosis, (b) be willing to participate in an advocacy training intervention,

and (c) agree to all study procedures. Participants lived in three states (TN, IL, and WI). Families were randomly assigned to a treatment or control group. Treatment group parents received a 24 hour advocacy training intervention and control group parents were given written information about adult services (and could participate in the full training after a 12-month waiting period). Though parents were the primary respondents in the larger study, and all parents had to agree to participate in an advocacy training intervention to be eligible, the age of their youth provides an opportunity to explore the lived experiences of youth with autism as they are supposed to take the reins of their own advocacy.

To examine the youth's role in decision making about adult services, data were collected directly from youth whose parents were assigned to the control group. Excluding treatment group families from this analysis allowed us to minimize the impact of the intervention on perceptions of services (particularly as person-centered thinking and planning was a focus of the intervention). Altogether, there were 75 participants in the control group; 10 of the parent participants declined to participate in this wave of data collection.

Participants

The sample for this study includes 43 youth with autism. To be included in the data collection analyzed in this study, the 65 parents had to agree that the youth was available for an interview with the research team and had a meaningful method of communicating with the team. "Meaningful communication" entailed having a reliable method of communication that could include verbal ability, sign language, and augmentative and alternative communication devices. Based on these criteria, 22 youth did not participate in this study, resulting in a final sample size of 43.

Youth were, on average, 21.10 years of age (range from 17.6 to 26.6). Most

participants were male (72.1%, $n = 31$). Many participants were White (74.4%, $n = 32$). All

participants had documentation from a medical provider or education professional indicating an

autism diagnosis. In addition, 44.2% ($n = 19$) of the participants had co-occurring ID. All but one

participant used verbal communication as their primary mode of communication. See Table 1.

Recruitment

Participants for the larger study were recruited in a variety of ways across the three states,

including through research registries, disability agencies, schools, and parent support groups.

Recruitment information was available via social media blurbs, flyers, and announcements on

websites. Youth for this study's analyses were offspring of the parents from the larger study, and

were recruited through their parent participant. For their participation in this interview, each

youth participant received $25.

Procedures

University Institutional Review Board approval was received for this project. The

interviews for this study were conducted as part of the third wave of data collection for the larger

project, approximately six months after treatment group families had participated in the parent

advocacy intervention. Interviews occurred between January of 2021 and June of 2021. All

interviews were conducted remotely over the phone or via zoom by trained research team

members. Specifically, each researcher completed a qualitative training as well as a mock

interview. When a researcher reached 100% fidelity on the mock interview, the researcher began

conducting interviews for this study.

At the beginning of the interview, the research team member introduced herself. All

interviews were recorded. The interview questions included: "How are you involved in making

decisions?"; "How do you decide which services you receive?"; "How do you decide whether you receive services in-person, over the computer, or not at all?"; "Who helps you make these decisions?"; and "Do your parents listen to you?". On average, each interview lasted 30 mins (range 20-45 mins). At the end of each interview, as a member check (Brantlinger et al., 2005), the participant had the option to revise any of their input. Fidelity to the interview protocol was 100% such that each participant was asked all the questions on the interview protocol.

Instrumentation

The questions in the interview protocol were developed based on a review of the literature about services and transition-aged youth with autism (e.g., Burke & Heller, 2016; Taylor et al., 2017). The interview protocol was reviewed by experts in autism research and adult services as well as parents of individuals with autism. It was also piloted with a young adult with a disability. Minor suggestions were made (e.g., small wording changes). Revisions to the interview questions based on this feedback were made, and the protocol was finalized.

Data Analysis

First, interviews were transcribed verbatim. Two research team members read each transcript multiple times to familiarize themselves with the data (Tesch, 1990). The research team used emergent design (Patton, 2002) to code the transcripts. Specifically, given the limited extant literature, an inductive data analysis strategy was needed to analyze the data. We had no a priori codes. Specifically, each team member independently coded the interviews. Using a word-by-word approach, they individually coded all text related to services. Each piece of data was compared with the other data, highlighted, and annotated with a specific phrase (Creswell, 2003). Each new piece of data was then compared with previously coded data to check if the new data were considered a new idea or can be an existing code. The research team met to compare codes

and resolve differences. Once all data were coded, the research team created a codebook. Then, the same team members used the codebook to re-examine the data. During this process, they determined whether new codes should be added to the codebook. The codes were grouped into categories and organized into themes grounded in the data. During the coding process, if there were any coding disagreements, the team members discussed codes until consensus was reached. During data analysis, the team also searched for patterns among the themes in relation to the youth with autism (i.e., presence/absence of ID, gender, state of residence).

Although uncommon in qualitative research, the frequencies of the themes are shared in this study. We did this for two reasons. By sharing the frequencies, the reader can determine the internal generalizability (Maxwell, 1992) of the themes. Notably, the frequencies do not impact the transferability of our findings. Rather, the frequencies illustrate the extent to which a theme was common among our data. The frequency counts are particularly useful when thinking of implications for service delivery and intervention. If a theme emerges around positive impacts of the pandemic on services (e.g., telehealth), it may be important to know the extent to which participants experienced that positive effect. The frequencies also show the diversity of the themes. For many of the interview protocol questions, there was variability in the responses. Sharing the frequencies of the themes highlights the diversity among participants' perceptions of services. Two research team members independently counted the frequencies of each theme. Inter-rater reliability was 100%.

Credibility and Trustworthiness

The authors made several efforts to ensure the credibility and trustworthiness of the themes. For example, a brief member check was conducted at the end of each interview. By conducting member checking, participants were able to assess the validity of the findings (Guba

& Lincoln, 1989). In addition to the member checks, the research team participated in weekly peer debriefing. During these meetings, the team discussed data collection and data analysis. Further, to refine themes, team members searched for negative cases during data analysis (Brantlinger et al., 2005). In addition, the team members have had extensive experience working with autistic youth. Their familiarity with the experiences of autistic youth was a strength in conducting this study and analyzing the data. Notably, each of the team members believed that autistic youth should be involved in choosing their own services. To address this bias, each team member recorded field notes and engaged in peer debriefing to identify and mitigate their biases. Names were replaced with pseudonyms and identifiable information within quotes have been removed.

Findings

Youth Involvement in Choosing the Types of Disability Services

Youth Fully Involved in Service Decisions

Over 20% (*n* = 10) of participants reported that they were involved in making service-related decisions. "Full involvement" was operationalized as being treated as being the primary decision-maker. Youth who were fully involved in decision-making could consult with others as long as they were, ultimately, making the final decisions. With the exception of one participant, all of the participants specifically focused on decisions related to educational services. Specifically, nine of the 10 participants spoke about high school services. For example, Daniel, a high school student from Tennessee, referenced his involvement in his Individualized Education Program (IEP) meetings. He shared, "If it's [a service need] very obvious to me, I ask for assistance and see what we can do to make that happen." Angel, a high school graduate, reflected on her experience in school sharing, "I made decisions based on how well I knew myself and my

learning needs." Similarly, Jack, a high school student from Wisconsin, reported, "I choose services when I think they are important." Only one participant referenced a non-education service. Nathan, a 19-year-old from Wisconsin, explained his involvement in supplemental security income (SSI). He reported, "I talk with my mom about it [SSI]. I figured out what I need and what will help."

Youth Partially Involved in Service Decisions

While not fully responsible for decision-making, several participants (14%, $n = 6$) reported that they had some involvement in making decisions about services. Unlike participants who were fully involved in making decisions about services, partial involvement indicated that the participants and at least one other person (e.g., a parent) made decisions about services. In full involvement, participants could consult others but did not share decision-making authority with any other individuals. For partial involvement, other individuals included: parents, adult service providers, and IEP team members. Isaiah, an 18-year-old from Tennessee, reported:

> A lot of times, I point out that there's something I'm currently struggling with, and I
> might need professional help. My mom is a speech therapist, and she has access to a lot
> of services and programs. She suggests [what could be helpful] and I agree.

Isaiah stating that he "agrees" with his mom suggests that they are engaging in shared decision-making. Other participants also reported shared decision-making about services. John, a 23-year-old from Illinois, reported he made some decisions and his mom made some decisions. He reported, "It was my decision to opt-out of transition services, but my mom made the decision about home and community services."

Absence of Youth Involvement in Service Decisions

The majority (58.1%, $n = 25$) of participants reported no involvement in service decisions. Specifically, 17 of the 25 participants who reported no involvement reported that they did not know about their services. Kara, an 18-year-old from Tennessee, reported, "I really don't know anything about services." Other participants provided responses such as, "I have no idea." The remaining eight participants straight-forwardly answered that they were not involved in any service decisions. Paige, an 18-year-old from Wisconsin shared, "I do not make any decisions." Similarly, Ralph, a 21-year-old from Tennessee who was enrolled in a transition program and employed at a clothing store, reported, "I do not do this [make decisions about services]. I don't even know how my mom does it."

Involvement in Choosing the Modalities of Services

Youth Fully Involved in Choosing the Modalities of Services

Altogether, 37.2% ($n = 16$) of the participants reported that they only had one option for the modality of each service. Thus, they were not involved in decision-making about modalities as there were no choices. Accordingly, only 27 participants had opportunities to be involved in decisions about service modalities. Of the 27 participants, only a few participants (18.5%, $n = 5$) reported that they were fully involved in decision-making. Matt, a high school student from Wisconsin, reported, "That [choosing the modality] is up to me. I think about safety, level of competence." Similarly, Ben, a 23-year-old from Illinois, reported, "I decided [virtual or in-person] after my mom gave me the options [about the services]." Notably, participant preference was noted when making choices about modalities of services. To this end, Luke, a high school student from Illinois, shared, "I like in-person [services]. Technology does not always work."

Youth Partially Involved in Choosing the Modalities of Services

Many participants (33.3%; *n* = 9) reported that they were partially involved in choosing the modality of the services. Andrew, who graduated with a regular diploma and was working in a supported employment setting, reported, "[I] talk with my mom about it…Just to see what [option] would be better." Other participants similarly reported including family in the decision-making about the modality of the service. Luke, a 23-year-old from Illinois, stated, "My mom always chooses in-person. I usually do so as well."

Youth Not Involved in Choosing the Modalities of Services

Just over one-half of participants (51.9%, *n* = 14) reported that they were not involved in decision making about modalities of their services. Some participants expressed that their parents decided for them. For example, Cody, who graduated from high school, reported, "I receive all services in-person. Mom checks them over for me." Similarly, Amy, who received a college degree in art therapy and was pursuing a master's degree, stated, "Overall, my mom decides for me about counseling and assistive technology services."

Extent to Which Families Support Youth Involvement in Selecting Services

All youth were asked who, if anyone, supported them to make decisions related to services: the majority (79.1%, *n* = 34) of participants reported that their families helped them. Many participants responded with similar responses such as "mostly my parents," "my mom," or "my dad." Justin, a 17-year-old from Tennessee, reported, "I always get help from my parents [when making service decisions]." Notably, while many youth relied on their families for support in decision-making, there were different types of supports across participants. For example, Laura, a 24-year-old from Wisconsin shared, "Mom and dad [support me] and [I] do a lot of self-reflection." In a different scenario, Gigi reported, "My mom will present me options

and then I pick from them." In yet another example, Wyatt, a young adult attending a post-secondary program in Tennessee, reported:

> Sometimes, I feel like I can fix it [depression] on my own. But certain times, it gets too severe to fix it by myself. There was one time when I was 16 and it got really serious. I kept trying to [get mental health services], but I couldn't do it by myself. My mom helped me find a counselor. With their [family] help, my mental health has greatly improved.

In addition to families providing various types of support to assist with decision-making, some participants reported receiving assistance from other individuals in decision-making. Specifically, of the 34 participants who reported their families assist with decision-making, 26.5% ($n = 9$) of the participants reported additional stakeholders (i.e., teachers, therapists, and outside organizations) assist in choosing services. Some participants ($n = 6$) who were either in high school or college reported that teachers assisted with decision-making.

Notably, most participants reported that their parents facilitated their involvement in decision-making. For example, when asked if their family listens to them during decision-making, a vast majority of the participants ($n = 38$) responded "Yes." Participants elaborated that their families "absolutely" listen to them or "listens very intently." Ben, a young adult from Illinois, reported that his parents are, "good, nice, and they are helpful." In contrast, three participants did not respond or were unsure of how to characterize their family's involvement and two participants reported that their parents did not listen to them. When probed, neither participant expounded with one participant stating they would rather "skip that one."

Patterns Across Participants

When exploring the themes in relation to characteristics of the youth, a few patterns were identified. Of the 10 youth who reported being fully involved in choosing their services, the

majority did not have ID ($n = 7$). Put another way, 29.2% of participants without ID reported

being fully involved in choosing their services whereas only 15.8% of the participants with ID

reported being fully involved in service decisions. Second, across the three states, participants in

Wisconsin (versus Tennessee and Illinois) more frequently reported full involvement in service

decisions. For example, of the 10 participants who reported full involvement in service decisions,

50% resided in Wisconsin. In addition, of the five youth that reported full involvement in

modality of service decisions, 60% resided in Wisconsin. Finally, male (versus female)

participants were more likely to report being fully involved in service decisions (90%, $n = 9$) or

selecting the modality of the service (66.7%, $n = 4$).

Discussion

It is critical for autistic youth to be involved in decisions about their services. Yet, it is

unclear the extent to which youth are involved in decision-making. This study had two main

findings. First, most participants were not fully involved in making decisions about services.

Prior research demonstrates that youth with autism (versus other types of disabilities) experience

less self-determination (Shogren et al., 2018). This study extends the literature suggesting that

low self-determination extends to decision-making about services. The minimal or absent

involvement in decision-making is especially problematic given the importance of services for

outcomes for autistic youth (Alverson & Yamamoto, 2017; Migliore et al., 2012; Myers et al.,

2015).

This study also suggests that some of the lack of (or minimal) involvement of youth in

decision-making about services may be due to insufficient opportunities. For example, many

participants reported not knowing about their own services. Limited knowledge about services

may prevent some youth from being involved in decision-making. Put simply, without ways to

learn about adult disability services, youth may not be afforded opportunities for involvement.

Another example of insufficient opportunities for involvement relates to service modalities.

Many youth were not involved in decisions about service modalities because there were no

options. Depriving youth of options about service modality inherently limits opportunities for

decision-making and, potentially, access and quality of services. The absence of options about

service modality is increasingly problematic as, for some autistic individuals, telehealth may be a

more accessible means to access services (Ellison et. al, 2021). Altogether, these findings show

that the limited involvement of some autistic youth may not solely be due to the characteristics or

support needs of the youth but rather to the shortcomings of the service delivery system.

Our second finding, however, suggests that involvement in service decisions varies in

relation to some participant characteristics and the type of service. Specifically, there were

patterns between involvement in decision-making and characteristics related to the participants

themselves (i.e., presence of ID, gender) as well as the locations of the participants (i.e., state of

residence). This finding suggests that certain individuals may be more or less prone to

involvement. Consider the presence of ID. As individuals with (versus without) ID may have

greater support needs (Eaves & Ho, 2008), more targeted efforts may be needed to include

autistic individuals with ID in decision-making. Further, female (versus male) autistic youth may

require more targeted intervention to ensure their involvement in decision-making. It is unclear

whether minimal decision-making among female (versus male) autistic youth is due to

camouflaging (Cook et al., 2021) or, perhaps, due to females having lower self-determination

than males (Shogren et al., 2018).

In addition, the state of residence mattered in relation to decision-making. In this study,

the states (IL, TN, WI) differed on several dimensions including the length of the waiting list and

availability of institutional settings (United Cerebral Palsy, 2022). The states also differed in

relation to HCBS spending for individuals with disabilities (i.e., Wisconsin spends the most

money on HCBS waivers, Tanis et al., 2020) and the prevalence of autistic youth in inclusive

school settings (i.e., Wisconsin has the highest degree of inclusion among autistic youth, Kurth,

2014). There may be other, unknown state differences. It is unclear which difference (or set of

differences) may explain the variability in decision-making among autistic youth. Future

research should consider more closely examining the impact of the state of residence on youth

decision-making.

Regarding the type of service, participants often were only fully involved if the service

was related to education. This finding dovetails with the another finding that teachers often

assisted with service decisions. To some extent, this finding aligns with prior research showing

that youth and families are most likely to guide services in relation to school (Friedman, 2018).

However, this finding also raises several questions: Why is it easier for youth to be more

involved in services at school versus out-of-school? Why may youth involvement in decisions

decrease over time? What provisions are in place during (versus out-of) school that support

youth involvement in decision-making? Further, in some ways, this finding may contradict the

extant research which shows that self-determination often increases with age (Shogren et al.,

2018). By understanding why youth are more likely to be fully involved in school decisions,

such supports can be replicated in other disability services.

It may be that policy facilitates youth involvement. The IDEA (2004) has provisions

reinforcing the importance of self-advocacy and self-determination of youth with disabilities.

Although IDEA does not flesh out ways for youth involvement (Sanderson & Goldman, 2022), it

establishes an expectation that youth, if possible, should attend IEP meetings. This prerequisite

may set the stage for youth to voice their concerns about education services. This finding suggests that when policies underscore the role of autistic youth, they are more likely to voice their opinions in relation to services.

While this study provided a launching point for understanding decision-making about services from autistic youth, there were also some limitations. For example, the sample was homogenous reflecting little racial and ethnic diversity and no linguistic diversity. Further, all parents of the youth agreed to participate in an advocacy training intervention. Thus, the transferability of findings is limited. It may be that the parent participants were individuals who were highly engaged in service access decisions—so engaged that they were willing to complete a rigorous advocacy intervention. It may be that the parents of these youth would be more likely to include their offspring in service access decision-making. Yet, in our study, we saw that most youth were limitedly involved in service access decisions. It may be that youth involvement is even more limited in the general population. Further, for inclusion in the study, parents of the youth had to agree that their youth would be available for the interview and had a form of meaningful communication. Thus, participants may only reflect individuals with "meaningful forms of communication" (as deemed by the parents) thereby further limiting the transferability of findings. Even with this inclusionary criterion, the sample was heterogenous in relation to functional abilities. Most studies about the lived experiences of autistic youth only reflect individuals without ID (Laugeson et al., 2015); this sample extends the literature by including youth with and without ID. Finally, this study included youth from ages 16 to 26. It may be that involvement in decision-making changes over time. Given the cross-sectional nature of this dataset, it is unclear whether such changes occur.

Directions for Future Research

To develop a holistic understanding of decision-making about services, research is needed with youth and their families. Based on this study, many autistic youth and families often make decisions about services together. However, to date, most research has only examined the perspectives of parents, specifically mothers, about services (Burke, 2012). This study suggests the importance of conducting research with the parent *and* the youth to understand decision-making about services. Dyadic studies wherein two family members participate (e.g., the person with a disability and the parent) can help develop a richer understanding of a phenomenon. Indeed, in the disability field, such studies can shed light on the differences and similarities in perspectives among parent-child dyads about a range of topics (e.g., Critchley et al., 2021). Future research should consider conducting dyadic interviews; specifically, an interview with the autistic youth, the parent, and the youth and parent together to inform a greater understanding about decision-making related to services.

Research is also needed to better understand the patterns of decision-making related to services. This study suggests that who (i.e., presence of ID and gender) and where (i.e., state of residence) matter in relation to decision-making. Future research may more closely examine these patterns to understand the direction of effects as well as to tease out the reasons for such patterns (e.g., why does gender matter in decision-making?). However, research may also investigate whether there are other patterns in relation to decision-making. For example, research may include more racially, ethnically, and linguistically diverse samples to determine whether there are any patterns in relation to decision-making. Research about parents of individuals with disabilities, including autism, suggests that parents from racial minority backgrounds and/or families who are emerging bilingual or multilingual learners are less likely to have their voices heard during decisions about services (Rossetti et al., 2021). Other characteristics may include

the help-seeking behaviors of youth with autism—do individuals who engage in help-seeking

perceive that they are relinquishing decision-making to someone else? It is important to identify

other patterns in relation to decision-making among autistic youth.

Implications for Policy and Practice

Policymakers may consider closely examining IDEA provisions and considering whether

to replicate language about self-advocacy and self-determination in other pieces of legislation. In

addition, policymakers should examine the jargon and bureaucracy required for adult disability

service navigation. Service delivery systems (and their respective policies) are complicated and

difficult to navigate (Hanley-Maxwell et al., 1995). By revising such policies to simplify them or

provide supports to autistic youth, there may be greater opportunities for youth to make decisions

about services.

Practitioners may also consider these findings when working with youth and families to

determine services. Indeed, practitioners may more closely consider youth who are prone to less

decision-making (e.g., females and/or individuals with ID) to identify innovative and

individualized ways to secure their opinions when identifying services. This finding may be

especially relevant for teachers who, according to this sample, also assisted in many decisions

about services. By utilizing strategies to target participation from female autistic youth and/or

autistic youth with ID, practitioners can help ensure that youth have their voices heard in service

coordination.

References

Abery, B. H., & Stancliffe, R. J. (2003). An ecological theory of self-determination: Theoretical

    foundations. *Theory in Self-Determination: Foundations for Educational Practice.* In M.

    Wehmeyer, B. Abery, D. Mithaug, & R. Stancliffe (Ed.), pp.25-42. Springfield, IL:

    Charles C. Thomas Publishing.

Alverson, C. Y., & Yamamoto, S. H. (2017). Employment outcomes of vocational rehabilitation

    clients with autism spectrum disorders. *Career Development and Transition for*

    Exceptional Individuals, 40, 144-155. https://doi.org/10.1177%2F2165143416629366

Aranki, J., Wright, P., Pompa-Craven, P., & Lotfizadeh, A. D. (2022). Acceptance of Telehealth

    Therapy to Replace In-Person Therapy for Autism Treatment During COVID-19

    Pandemic: An Assessment of Patient Variables. *Telemedicine and e-Health, 28*, 1342-

    1349. https://doi.org/10.1089/tmj.2021.0397

Barnard-Brak, L., & Lechtenberger, D. (2010). Student IEP participation and academic

    achievement across time. *Remedial and Special Education, 31*, 343-349.

    https://doi.org/abs/10.1177/0741932509338382

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative

    studies in special education. *Exceptional Children, 71*, 195-207.

    https://doi.org/10.1177%2F001440290507100205

Burke, M. M. (2012). Examining family involvement in regular and special education: Lessons

    to be learned for both sides. *International Review of Research in Developmental*

    Disabilities, 43, 187-218. https://doi.org/10.1016/B978-0-12-39826102.0005-2

Burke, M., & Heller, T. (2016). Individual, parent and social–environmental correlates of

    caregiving experiences among parents of adults with autism spectrum disorder. *Journal*

    of Intellectual Disability Research, *60*, 401-411. https://doi.org/10.1111/jir.12271

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic

    review. *Clinical Psychology Review, 89*, 102-118. doi.org/10.1016/j.cpr.2021.1.102080

Creswell, J. W. (2003). A framework for design. *Research design: Qualitative, quantitative, and*

    mixed methods approaches, 9-11.

Critchley, E., Cuadros, M., Harper, I., Smith-Howell, H., & Rogish, M. (2021). A parent-sibling

    dyadic interview to explore how an individual with autism spectrum disorder can impact

    family dynamics. *Research in Developmental Disabilities, 111*, 103-118.

    https://doi.org/10.1016/j.ridd.2021.103884

Eaves, L. C., & Ho, H. H. (2008). Young adult outcomes of autism spectrum disorders. *Journal*

    of Autism and Developmental Disorders, 38, 739–747. https://doi.org/10.1007/s10803-

    007-0441

Ellison, K. S., Guidry, J., Picou, P., Adenuga, P., & Thompson, E. D. (2021). Telehealth and

    autism prior to and in the age of COVID-19: A systematic and critical review of the last

    decade. *Clinical Child and Family Psychology Review, 24*, 599-630.

    https://doi.org/10.1007/s10567-021-00358-0

Friedman, C. (2018). Participant direction for people with intellectual and developmental

    disabilities in Medicaid Home and Community Based Services waivers. *Intellectual and*

    Developmental Disabilities, 56(1), 30-39. https://doi.org/10.1352/1934-9556-56.1.30

Glaser, B., & Strauss, A. (1967). Grounded theory: The discovery of grounded theory. *Sociology,*

    12(1), 27-49. https://doi.org/10.4324/9780203793206

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Sage Publications, Inc.

Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. M. (1995). The second shock: A

    qualitative study of parents' perspectives and needs during their child's transition from

    school to adult life. *Research and Practice for Persons with Severe Disabilities, 20*, 3-15.

    https://doi.org/10.1177%2F154079699502000102

Kim, K. H., & Turnbull, A. P. (2004). Transition to adulthood for students with severe

    intellectual disabilities: Shifting toward person-family interdependent planning. *Research*

    & Practice for Persons with Severe Disabilities, 29, 53-57.

Kurth, J. A. (2015). Educational placement of students with autism: The impact of state of

    residence. *Focus on Autism and Other Developmental Disabilities, 30*(4), 249–256.

    https://doi.org/10.1177/1088357614547891

Laugeson, E. A., Gantman, A., Kapp, S. K., Orenski, K., & Ellingsen, R. (2015). A randomized

    controlled trial to improve social skills in young adults with autism spectrum disorder:

    The UCLA PEERS® program. *Journal of Autism and Developmental Disorders*, *45*(12),

    3978-3989. https://doi.org/10.1007/s10803-015-2504-8

Maxwell, J. A. (1992). Understanding and validity in qualitative research. *Harvard Educational*

    Review, 62, 279-300. https://doi.org/10.17763/haer.62.3.8323320856251826

Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and

    postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin, 55*,

    176-184. https://doi.org/10.1177%2F0034355212438943

Myers, E., Davis, B. E, Stobbe, G., & Bjornson, K. (2015). Community and social participation

    among individuals with autism spectrum disorder transitioning to adulthood. *Journal of*

Autism and Developmental Disorders, 45, 2373-2381. https://doi.org/10.1007/s10803-015-2403-z

Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal,

experiential perspective. *Qualitative Social Work, 1*(3), 261-283.

https://doi.org/10.1177/1473325002001003636

Rossetti, Z., Burke, M. M., Hughes, O., Schraml-Block, K, Rivera, J. I., Rios, K., Tovar, J. A., &

Lee, J. D. (2021). Parent perceptions of the advocacy expectation in special education.

Exceptional Children, 87(4), 438-457. https://doi-org/10.1177/0014402921994095

Sanderson, K., & Goldman, S. E. (2022). Understanding the characteristics and predictors of

student involvement in IEP meetings. *Journal of Special Education, 56*, 3-13.

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L.

(2012). Postecondary education and employment among youth with an autism spectrum

disorder. *American Academy of Pediatrics, 129*, 1042-1049. https://doi-org/10.1542/peds.2011-2864

Shogren, K. A., Palmer, S. B., Wehmeyer, M. L., Williams-Diehm, K., & Little, T. D. (2012).

Effect of intervention with the Self-Determined Learning Model of Instruction on access

and goal attainment. *Remedial and Special Education, 33*, 320-330.

https://doi.org/10.1177/0741932511410072

Shogren, K. A., Shaw, L. A., Raley, S. K., & Wehmeyer, M. L. (2018). Exploring the effect of

disability, race-ethnicity, and socioeconomic status on scores on the self-determination

inventory: Student report. *Exceptional Children, 85*, 10-27. https://doi-org/10.1177/0014402918782150

Shogren, K. A., & Ward, M. J. (2018). Promoting and enhancing self-determination to improve

the post-school outcomes of people with disabilities. *Journal of Vocational*

Rehabilitation, 48(2), 187-196. https://doi.org/10.3233/JVR-180935

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015).

Relationships between self-determination and postschool outcomes for youth with

disabilities. *The Journal of Special Education, 48*, 256-267.

https://doi.org/10.1177/0022466913489733

Tanis, E. S., Lulinski, A., Wu, J., Braddock, D., & Hemp, R. (2020). The state of the states in

intellectual and developmental disabilities. *Boulder: University of Colorado*.

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017).

Training parents of youth with autism spectrum disorder to advocate for adult disability

services: Results from a pilot randomized controlled trial. *Journal of Autism and*

Developmental Disorders, 47(3), 846-857. https://doi.org/10.1007/s10803-016-2994-z

Tesch, R. (1990) Qualitative research: Analysis types and software tools. *Hampshire, UK*: The

Falmer Press.

United Cerebral Palsy. (2022). The Case for Inclusion: Blazing Trails to Sustainability for

Community Disability Services. Available at

https://caseforinclusion.org/application/files/1716/4658/7147/Case_for_Inclusion_2022_

Blazing_Trails_to_Sustainability_for_Community_Disability_Services.pdf

Valdez, R. S., Rogers, C. C., Claypool, H., Trieshmann, L., Frye, O., Wellbeloved-Stone, C., &

Kushalnager, P. (2021). Ensuring full participation of people with disabilities in an era of

telehealth. *Journal of American Medical Informatics Association, 28*, 389-392.

https://doi-org/10.1093/jamia/ocaa297

Wehmeyer, M.L., & Shogren, K.A. (2016). Self-Determination and Choice. In: Singh, N. (eds)

    Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities.

    Evidence-Based Practices in Behavioral Health. Springer, Cham. https://doi-

    org.proxy2.library.illinois.edu/10.1007/978-3-319-26583-4_21

White, L. C., Law, J. K., Daniels, A. M., Toroney, J., Vernoia, B., Xiao, S., & Chung, W. K.

    (2021). Impact of COVID-19 on individuals with ASD and their caregivers: A

    perspective from the SPARK cohort. *Journal of Autism and Developmental Disorders*, 1-

    8. https://doi.org/10.1007/s10803-020-04816-6

Table 1

Participant Demographics

	% (*n*)
Gender	
Male	72.09% (31)
Female	27.91% (12)
Race	
White	74.42% (32)
More than one race	13.95% (6)
Asian	6.98% (3)
Black or African American	2.33% (1)
Other	2.33% (1)
Ethnicity	
Not Hispanic/Latinx	95.35% (41)
Hispanic/Latinx	4.65% (2)
Intellectual Disability	
No	55.81% (24)
Yes	44.19% (19)
Communication	
Verbal	97.67% (42)
AAC User	2.33% (1)
State	
Tennessee	41.86% (18)
Wisconsin	30.23% (13)
Illinois	27.91% (12)

Note: AAC = Augmentative and Alternative Communication