



Children and Youth with ASD:

Services, Transition, and Future Services

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**Maine Developmental
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Introduction

In December 2020, the Maine Developmental Disabilities Council worked with the Autism Society of Maine to conduct two surveys and three focus groups to assess how children and youth with Autism Spectrum Disorders (ASD) experienced the service system, including: the system of transitioning to adulthood, whether there are services and supports that families of children and youth with ASD are struggling to access, and what types of services could be created to make for the best supports possible.

When organizing both the surveys and focus groups it became clear that families and self-advocates are tired and feel like previous involvement was ineffective. One family of an adult stated, “they don’t even talk to us. The State looks for opinions from providers but self-advocates and our families? We are just the commodity that the State and Providers use. Everyone else gets advice about COVID from the State but we are moved around by the Provider agencies. I am not saying we don’t need our Provider! But it would be nice if the State viewed us as people with value as well.” MDDC and the ASM have conducted many surveys and focus groups. It is clear that the low numbers are indicative of COVID fatigue, survey fatigue and frustration at how slowly systems change.

Description of respondents

ASD Service Survey: 44 family members of children or youth with ASD completed the ASD Service Survey. 80% of respondents represented children between the age of 5-18, the typical age range for school aged children. 9% of the respondents were representing children under the age of 5 and 11% of respondents represented adults over the age of 18.

Transition Survey: 18 individuals with ASD or their family members completed the Transition Survey. 94% of the respondents (17) were family members of individuals with ASD while only 1 respondent was an individual with ASD. 12 of the represented were adults while 6 were currently going through the transition process to adult services.

Transition Focus Group: 4 guardians of youth with ASD participated in the transition focus group where they responded to questions related to their experiences navigating the process of moving from children’s to adult services.

Future Services Focus Groups: Two focus groups were conducted to assess types of services that are needed but do not currently exist. The first group included 5 mothers of adults with ASD who are eligible for waiver services and considered to have high service needs. The second group included 6 individuals, 5 of which have ASD. Most of the individuals are considered “high” functioning and receive services either through the waiver, through the mental health system, or are not eligible for any services whatsoever.

Executive Summary/Impressions

Despite the low numbers of respondents, taken together the focus groups and surveys did provide some interesting trends.

The ASD Service Survey indicated relatively strong satisfaction with services. However, respondents clearly expressed concern about growing waitlists for services in both the children and adult service sectors. The transition survey and all three focus groups discussed how difficult the waitlists were. Advice was clear, stay in the school system and the children's system for as long as possible so as to prevent getting on the adult waitlist with no services at all. Many talked about how they were transitioning to a waitlist. When asked if anybody talked about what could be done while on the waitlist the response was "I'm feeling very nervous about adult service because I have been hearing that it is the cliff – keep your child in special education as long as you can."

Another theme among the surveys and focus groups was concern about the high turnover rates for both direct service professionals and case managers. Concerns ranged from the lack of knowledge that staff has about the condition of ASD and that professionals either choose not to serve people with ASD or they assume that people with ASD are like the generic training they received, become disenchanted and unsupported and quit.

65% of survey respondents and none of the families were able to access respite. The reason for not getting respite ranged from not feeling safe to having to find the respite provider themselves and having exhausted their natural support system. "Respite is not really being offered to us. We have not had respite for 8 years. The last time I tried to get it we were offered a man for my daughter who is minimally verbal so we turned it down."

Transition was discussed at length in the transition survey and focus groups. Both datasets describe a system in which families were asked to connect information from a variety of places (OADS, Case Manager, School, VR) and to put all the pieces together into a process that made sense for their family. It was more than just the transition focus group, however, that discussed how difficult a process but the adult "dreams" focus group described it as well. The overall belief was that transition begins to late. "Honestly getting information sooner until waiting until one year and throwing everything all at once. [Someone to say] You need to be thinking of this and you need to be thinking of that. It is a weird position because it is the schools saying you can't get services" yet it is the schools job to move people through the planning process. Survey responses included the feeling of not being heard, school staff not engaging in the process, not having a transition plan at all, finding independent living, finding an adult case manager, and the overall anxiety of the process.

Perhaps the most interesting conversations were conducted by the two adult focus groups that analyzed what they would like services and supports to look like. Recommendations included:

- Change of the paradigm of a habilitative model of services to a growth model. Adults with ASD who have high service needs experienced a service system is aimed at *keeping existing skills only* but not *developmentally continuing to develop skills*.
- Create opportunities for adults who are considered “high functioning” to understand, learn, and practice social skills in order to be successful.
- Develop a flexible system in which those who are not eligible, or support is not adequate, are able to self-pay for services such as case management.
- Adopt a waiver such as what Connecticut offers for individuals with ASD who do not have an intellectual disability yet have at least two functional limitation of daily living. Services range from social skills support, access to mentors, and job support. Cost is capped annually.
- Require that there be a paid self-advocate advisor and parent advisor position in all provider agencies to ensure that individual and family voice is heard as loud as the voice of business.
- Develop, incentivize, or create inclusive, yet supported, housing opportunities in the community.
- Create a service where an adult with ASD can practice staying at a different place overnight. This is different from respite as its focus is skill-building to teach an adult who may never have had the opportunity to stay outside of a family home how to spend the night somewhere else.
- Offer Self Directed Services for any level of disability

“Once my son turned 18 nothing was about moving him forward just what we could provide. I learn something new every day why can’t he learn something new every day.”

Results

ASD Service Survey

Age of Initial Diagnosis(n=44): 61% of respondents (21) reported that their child was diagnosed older than 3 years old while the remainder (39%, 17) reported that their child was initially diagnosed between 13 and 24 months of age. **While the total respondents of this survey are only 44 people this limited snapshot does indicate that Maine may lag behind national data which showed that 71% of children with ASD were identified in 2016 by the age of 3 years.¹**

Current Services(n=43): 74% of respondents reported that their child currently was eligible, and received special educational services through an Individual Education Plan. 23% (10) indicated that they received services through CDS. While only 4 children were reportedly under age 5 it can be assumed that 6 children remained receiving educational services as a 5-year-old through CDS. An additional 4 children (9%) received accommodations through the school with a section 504 plan.

56% of the respondents accessed case management for their child(ren). In addition, many children also received at least one therapy. The most common (56%, 24) received speech therapy while 47% (20) received occupational therapy and 19% (8) received Physical Therapy.

25% of respondents reported that their child(ren) received community therapy through a MaineCare service. Most (21%) received Section 28 Home and Community Based Services while only 5% received Section 65 Home and Community treatment Services. It was not specified if Applied Behavioral Analysis (ABA), one of the most common treatment strategies for individuals with ASD, was part of the services accessed through Section 28 but it is a service that is offered under the specialized portion of that MaineCare section.

25% (12) indicated that they accessed other services. 75% of those respondents indicated that their child received Counseling, Psychiatry, or assistance with Medication Management. Other services listed included ABA through private insurance, social skills group, and residential hospitalization.

43% (19) of all respondents children or youth are waiting to be able to access some sort of service. The largest percentage of those 19 children are waiting for Section 28 services (42%). The next most waited for services include Speech Therapy and Case Management (tied at 16%)

1 Centers for Disease Control (2016) [Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016](https://www.cdc.gov/mmwr/volumes/69/ss/ss6903a1.htm?s_cid=ss6903a1_w). Morbidity and Mortality Weekly Report. Retrieved on 1/14/2021 from:
https://www.cdc.gov/mmwr/volumes/69/ss/ss6903a1.htm?s_cid=ss6903a1_w

Two respondents' children are waiting for Occupational Therapy or a service that is listed on the IEP. Other individual respondents reported waiting for Counseling, Section 21 waiver, Psychiatry, Section 8 housing voucher, Section 65 HCT services, and CDS services.

How many meetings do you attend each year? (n=44) 30% of families reported that they attend more than 6 meetings per year. 57% of families reported that they attend 2-5 meetings to plan for services for their child(ren). 16% reported that the number of meetings can be as high

"We really need better diagnostic for women and LGBTQ nonwhite and people often need to pay out of pocket. I think it would also be beneficial of case management services so that if people are in therapy case management would be open to them. I was having a meltdown but I didn't have MaineCare so I couldn't get case manager. My case manager came today to hold me accountable to pay bills and organize. I didn't know how to do this stuff and the case manager was able to act as a translator – having more prevalence of case manager so we don't have to get to the crises point."

as 6-10 meetings. 14% reported that those meetings number 11 or more. 14% reported that they either don't attend meetings or they only have 1 meeting per year.

Case Management

30 respondents of the children's service survey expressed considerable satisfaction with the case management system when asked to react to the prompt "My Case Manager listens and responds to my concerns, questions and ideas." **90% of the respondents that had case managers replied with a resounding Agree or Strongly Agree.** Yet even among those who strongly approved of their case manager there were concerns about the large

caseloads that case managers seem to have and that this makes connecting with them difficult at times. The high turnover rate was also brought up during the individuals with ASD focus group: "I'm my own rep-payee now. I am going to talk to my case manager to sign up on an Able account but I am not sure how I can get it and I am waiting for a new case manager. (Lots of turnover) I am working on filling out paperwork for rent rebate. Hopefully by April." The focus group was conducted early January.

Case management was a critical service for adults who were "high functioning" in order to get support in filling out paperwork and organizing. However, both the adults with ASD who were able to advocate for themselves and the family focus group that represented adults with ASD who were not able to advocate for themselves acknowledged that sometimes they needed to shop around for the right case manager for their family. "You have a child case manager but when they turn 18 you need to get an adult case manager to get the waitlist. We had to go through multiple adult case managers adult until we found the right fit for us."

Individuals who are on waitlists for waivers or are not eligible for adult DD services still may need case management. The focus group for adults with "lower" service needs expressed that one significant gap in the system is the ability to self or insurance pay for case management.

Some members expressed frustration at the fact that they couldn't purchase a case manager's services without being eligible for Waiver services.

"I don't know what is out there so I don't get any help with my autism. I don't get a case manager and I tried but I get rejected because I can't get one – I can't even offer to pay cash. I can't pay myself with case managers. I need a case manager. My parents are on the old side and I would really benefit from having someone. I would need some coaching for VR and I don't know how to go that route. I need someone to work with me."

Another member expressed that they are on a waitlist for Section 29 but cannot get MaineCare until the waiver slot is actually available, and how frustrating it is to wait for services.

Provider Satisfaction

19 respondents of the children's services replied to the statement "**My child's in-home support/community support meets my child's needs.**" **80% of these respondents agreed or strongly agreed that their child's in-home support/community met their child's needs.** The remaining 20% (2 disagreed, 2 strongly disagreed) indicated that they have not been able to access the service due to being on a waitlist or having a child with compromised health and fear of COVID.

"We had great difficulty finding people available to work. Then we had to find someone who was the right fit to work with my Son. After a few months, it happened thankfully. The stretch without services was brutal."

The trend of strong satisfaction continued with the statement "My child's service providers coordinate and communicate the services to meet my child's needs." Where **89% of respondents** (n=37) indicated that they **agreed or strongly agreed** with the service providers communication and coordination activities. Similarly to previous questions, only 4 respondents indicated dissatisfaction and only 1 respondent strongly disagreed with the statement.

All 44 respondents replied to the statement "**My child's Primary Care Provider/Doctor knows about the services my child receives.**" 84% agreed or strongly agreed with the statement while 16% either disagreed or strongly disagreed.

During the focus group of families who have adults in the adult service system respondents expressed more concern over the provider agencies and issues around quality and oversight for providers.

"There is no room for oversight. They [the provider agency] care about how they **look**. So, if my son has a medication error – when it is on the report somehow my son is blamed for it." The group discussed how they have multiple experiences with agencies appearing threatened when a parent brings issues up." Concern was brought up that professionals seem to say that something is "against an individual's rights" in a way that is counterintuitive to how this group understood rights. One mother reported that she asked for her son's needed visual supports but the agency said that limited his choices. "But that is the way he can HAVE choices," a different parent

replied. There clearly appears to be the need to have a discussion about how individual rights are interpreted. “It becomes so easy for providers to use choice to make the minimal decisions. Taking the concepts of self determination so that staff can become lazy or provider focused.” “People were trained in person centered practices were drowned out when institutionalized and lawyers talked about rights and law. I want to change the power shift. Providers should earn being quality. Supervisors are so barely trained in so many providers organization and it is shocking.”

Respite

Many people still need help accessing services. 45% replied that they strongly agreed that they need help accessing respite care. Surprisingly to this author, only 14% indicated that they needed help accessing dental care.

Access respite care was a topic that came up during the transition focus group. None of the families had been able to access respite. The reason for not getting respite ranged from not feeling safe to having to find the respite provider themselves and having exhausted their natural support system. “Respite is not really being offered to us. We have not had respite for 8 years. The last time I tried to get it we were offered a man for my daughter who is minimally verbal so we turned it down.”

“Maybe [respite] 2x a month where my child can go to a house for a weekend to give him a halfway house where he can have a weekend experience. My son has never slept anywhere else. We have respite money but we don’t know how to spend it. We need help finding. Wouldn’t that be a savings because we would get the break we need and he would have an opportunity to be able to sleep somewhere else.”

The family of adults with ASD who receive waiver services agreed that respite was also a significant challenge. But respite for these families was also a significant gap. “For parents who have 24/7 care that needs respite for a few hours. Maybe 2x a month where my child can go to a house for a weekend to give him a halfway house where he can have a weekend experience. My son has never slept anywhere else. We have respite money but we don’t know how to spend it. We need help finding. Wouldn’t that be a savings because we would get the break we need and he would have an opportunity to be able to sleep somewhere else.”

A summary of the responses about needs is in the table below.

I still need help accessing	Strongly Agree	Agree	Disagree	Strongly Disagree
Childcare (n=18)	28%	28%	39%	5%
Respite (n=22)	45%	23%	27%	5%
Can Access All that we Need (n=44)	9%	48%	39%	4%
Dentist (N=28)	7%	7%	50%	36%

21 respondents listed other needs that they have which included:

Access Medical/Dental/Mental Health that understands ASD	24%
Access to HCBS type services	19%
Access to Social/Recreational/Support Groups	19%
Education/Training/Technical Assistance for Educators	19%
Access to Educational Services	14%
Access to Assistive Technology	10%
Stable Workforce	14%
No Waitlists for Adult System	14%
Early Identification	10%
Better Coordination/Communication between home and school	10%
Short (a few hours) respite	5%
General Awareness ASD	5%
More Funding	5%

HealthCare/Mental Health

I am awed that we don't have more quality standards for people charged with the mental health of our children. I am awed that mental health professionals and doctors can say that "I don't serve people with I/DD" because they can't cope with interacting with our kid."

Both focus groups that represented adults with high and low service needs discussed the healthcare system and mental health system. Adults with ASD who are considered "high functioning" discussed how mental health concerns can also occur for individuals with ASD yet the mental health system is ill-prepared to work with the population. "There isn't a one-size fits all treatment and even for the same person, different interventions work differently as they develop." Those

who represented individuals considered “low functioning” were also frustrated. “I am so sick of doctors who work with people with DD/dual diagnosis there are counselors that work in substance and education who say they can work with my son but they are absolutely dangerous to people with DD Dual diagnosis. I am awed that we don’t have more quality standards for people charged with the mental health of our children. I am awed that mental health professionals and doctors can say that “I don’t serve people with I/DD” because they can’t cope with interacting with our kid.”

One light during COVID was telemedicine for some adults with ASD as it allows them to be engaged with the health system in ways that didn’t work before. “I am a huge fan of telemedicine. My physical therapy and behavioral therapy. I used to half to cancel if I wasn’t up to going out. So that has really opened up my door.” However, the complications of COVID is making appointments and connecting to new providers.

“One challenge that higher functioning adults face is filling out forms in doctors’ offices. I literally sweat when I fill them out. I had one case when the receptionists asked me what my daughters birthdays is and I froze. I couldn’t get it out. The receptionist was totally disgusted with me. Because we don’t exhibit whatever we need to exhibit the assumption is that you are “normal” and that is something that is hard. But now I can say I am autistic “give me a break.” Because I think that kind of awareness needs to be raised. The perception of autism is very narrow.” This sentiment was echoed by other focus group members: “I wish there was a check box that I could check that says “Autistic” and then I could get an interpreter to help me fill things out and have initial conversation.”

Crisis System

For example, “Crises workers also need some help with communication because they treat people like neurotypical people so people with autism don’t get the help that they need. Crises workers do like to work with mental health – they don’t understand me but I don’t understand them either.”

Transition Survey and Focus Group

Guardianship:

Of the 12 adult individuals with ASD represented in the survey 58% were under full guardianship. 25% of the respondents had a Supported Decision Making Agreement while one of the remaining respondents had limited guardianship and the other had a power of attorney agreement. Not one of the 12 respondents was their own guardian.

The focus group participants spoke about guardianship being one of the easiest parts of the process. Each family shared a different journey that ultimately ended in full guardianship. When asked about whether they had considered alternatives one family was “going to do supported decision making but I am not doing that because I didn’t realize how much work it is. It is too hard to get access to the medical information / medical assistance. I didn’t realize that

even partial guardianship eliminates the ability to be engaged in his health care. We are going to full guardianship.”

Another family stated: “They didn’t ask us anything about supported decision making. The doctor had to fill out a form, the psych filled out a form, and the judge read the forms and asked my son if he was on board. Everyone was for guardianship so it was just done over the phone due to covid.”

Transition Plan

Part of the purpose of the transition survey was to gauge people’s experiences as they go through or had gone through the transition process. The only formalized transition process exists through the special education system Individual Education Plan (IEP) process which requires a transition plan after the age of 14. All but 1 respondent engaged in the transition process. **When asked if they had/have a transition plan 53% of respondents either disagreed (18%) or strongly disagreed (35%).** While in almost converse proportions 47% of the respondents either agreed (18%) or strongly agreed(29%). 8 of the 9 respondents elaborated on why the transition plan didn’t work. 3 respondents shared that there was no transition plan at all. 3 stated that the transition plan lacked details. The remaining two comments were about the lack of knowledge that schools have about adult services and the inadequacy of preparing for real daily life for people who are “low functioning.”

The next set of questions were geared at determining whether or not the transition plan assisted in actually moving the person to the next step in adult life. To the question “did the transition plan help” only 8 responded. The reactions were split down the middle where 50% Disagreed and 50% either strongly agreed or agreed. 4 respondents answered “whether the plan assisted transitioning to post secondary education”. 75% responded that it did not help while only 1 person agreed that it did help transition to post-secondary education. 7 people responded to the statement that “the plan helped transition to employment”. Again, the reactions were split. 4 of the respondents disagreed or strongly disagreed while 3 either agreed or strongly agreed. The most successful outcome for the transition plan was being transitioned to the waiver, or onto a waitlist for the waiver. 10 respondents replied to the prompt where 70% agreed or strongly agreed that the transition plan assisted. The remaining 3 either disagreed or strongly disagreed.

*Our daughter is 18. Our Community Case Manager has started the process. I have taken a workshop with MPF. At first I felt like I had a pretty good idea but then you get to that [transition] age and it feels like it is so much. **I am getting confused about things that I thought I understood. I had a meeting with someone with OADS had a meeting and I thought it was VR.**”*

Another family discussed that staying in the school system additional years was only offered after graduation had occurred. “He officially graduated last June but is doing a post grade year because we fell off the cliff hanging. Transition is sitting and waiting.” Another family member expressed her sadness that “The older that these get it doesn’t seem they get the opportunities or

recognized because they are grown up. They are no longer a child with a diagnosis. They are forgotten.”

They basically gave a triennial IEP with a little more about adding a co-existing an ID diagnosis for eligibility in the future. I don't know if it was really helpful but that was when I finally knew what year my child would be graduating with a diploma. They assumed that we would be going for the certificate of completion – so she is now on track for Diploma

All three recipients spoke about the transition planning process for the school as being a meeting that occurred during the last 15 minutes of an IEP meeting. “They basically gave a triennial IEP with a little more about adding a co-existing an ID diagnosis for eligibility in the future. I don't know if it was really helpful but that was when I finally knew what year my child would be graduating with a diploma. They assumed that we would be going for the certificate of completion – so she is now on track for Diploma.”

When asked what would have been helpful from the school system the reply was “It would make it better if schools educated the process far earlier than transition. (age 18)

Parents need to know what is coming down the line as opposed to show up at a meeting where there is a softball team worth of people at the table giving you information – it can be overwhelming. It would be easier to get the information in smaller chunks.” The other parents agreed. “Honestly getting information sooner until waiting until one year and throwing everything all at once. [Someone to say] You need to be thinking of this and you need to be thinking of that. It is a weird position because it is the schools saying you can't get services” yet it is the school's job to move people through the planning process.

The bottom line is that transitioning from the school to adult service sector is not just done in schools but through other venues. One mother stated “Our daughter is 18. Our Community Case Manager has started the process. I have taken a workshop with MPF. At first I felt like I had a pretty good idea but then you get to that [transition] age and it feels like it is so much. **I am getting confused about things that I thought I understood. I had a meeting with someone with OADS had a meeting and I thought it was VR.**” Another parent spoke about how it took 1.5 years to collect all the documentation necessary to document that Section 21 was the necessary level of support for their child and pondered whether every parent had the ability to actually collect and compile all the information necessary for transition. 45% of the transition survey respondents noted how much parent involvement was necessary.

There was one family member that had a very positive experience with transition. Her young adult went to a Special Purpose Program and had “a transition specialist. They would work on employment, post-secondary, and independent living to identify goals to get there. That person was with him for 4 years. Her person was just to focus on the transition. I felt like that was what private and public schools need. The plan should be working with the youth – its that youth involvement that is so lost. You really need to know the youth. That is why you need an external person to look at the youth to look at strengths and have a good adult world.” The other family members in the group were in complete agreement with that sentiment.

60% of respondents need information about independent living. As the data shows, 54% the respondents still need additional information about the process itself, how to find a job, or how to go on to college. Only 33% responded that they need assistance locating an adult medical provider.

In answering the question, “What would have been more helpful about the transition process?”, 9 people responded. **The most common response was that the school didn’t engage, there were low expectations for the youth and that school staff do not understand the adult system.** Answers are below.

School didn't engage	5
Low expectations for youth	4
School staff don't understand adult system	4
Having team members actually and actively engage	3
School staff says things are available in adult system when they are not	3
Earlier Diagnosis	2
School creates false environments that set youth up to fail	2
Currently Transitioning	1
Earlier Transition Help	1
Everything was helpful	1
System is Complex	1

11 Respondents answered the question about what the biggest barriers were during transitioning. 45% of respondents noted how much parent involvement was necessary. 27% stated that it was very difficult to go from the entitlement system in children to learning about the eligibility system of adulthood. Other responses included the feeling of not being heard, school staff not engaging in the process, not having a transition plan at all, finding independent living, finding an adult case manager, and the overall anxiety of the process.

Waitlists

For most of the families who attended the transition focus group the future felt dimmer, transitioning to a waitlist. When asked if anybody talked about what could be done while on the waitlist the response was “I’m feeling very nervous about adult service because I have been hearing that it is the cliff – keep your child in special education as long as you can.” The advice to continue receiving children’s Section 28 services for as long as possible was also suggested but that system also has flaws. When the focus group families were asked the question “what they would change regarding the service system today?” the answers covered issues around not just the adult waitlist but the children/youth section 28 service as well,

“Transition is sitting and waiting”

“They suggested that we stay on 28 while we are on the waitlist until we are picked up on the waiver.” and “I would prefer her to be able to access the 20 hours she is eligible for. The turnover is crazy. I am now on my 25 provider.” This family had never received the full 20 hours because of the regular turnover in staffing they experienced.

Vocational Rehabilitation

When asked about Vocational Rehabilitation, members of the focus group expressed considerable frustration - from VR being invited to the transition planning meeting and not attending to frustration at the lack of understanding of the characteristics of ASD and how that relates to successful employment. “The only service we have right now is VR and that has been the worst experience. We are through our third company working with him – multiple job coaches. Getting guardianship has been the easiest part of the whole deal. We can’t find a job for him – someone willing to hire him.” This mother told a story in which her son had determined that he wanted to stock shelves. She had a number of job placements but nobody was willing to hire him. Now she is concerned because VR is thinking about trying him at a new job but her son has it in his mind that he will be stocking shelves and she is concerned that he will grow frustrated. “employers like saying yes we want the free 8 week trial but it never ends in a job. I’m concerned that there will be a lot of behaviors because first he figured out he wants to do – and now they want to find other things.”

Another family expressed concern about the lack of VR’s sensitivity to the characteristics of ASD. “These people from VR don’t understand how rigid [people like my son] is – he got lost when we pushed him to [work in] the cafeteria.” Another family spoke about how when her son gets frustrated he has learned the coping skill to vocalize his frustrations, yet “VR will say things like “to get hired he can’t make comments.” But if he doesn’t make comments he will have a more challenging behavior when he gets frustrated. They don’t understand that he has autism and says he can’t do it – without offering or teaching something else. It is not a light switch time to turn off autism. Then the turnover with Job Coach as well. A new job coach came in and my son was sitting on the floor stocking shelves. She said “you can’t sit on the floor?” That put my son in a panic – immediate change and he went running around the store trying to get away from this job coach.”

The families spoke at length about the need for additional training for DSP, BHP, Job Coaches, Mental Health Professionals, and School Staff. They all agreed that the characteristics of ASD are very different from other disabilities and more understanding and competency is needed in the professional field.

Another family spoke about how she has not had much help with transition and has done “most of it on my own.” When asked about VR she replied that “the lady was really nice but they didn’t offer much because he wanted to go to college.” Unfortunately, a few months after transition this youth had to be hospitalized.

Future Services, Dreams Focus Groups

Services need a growth model, not just a habilitative model

One of the main conversations that the group representing adults with high service needs had was about how the existing service system is aimed at **keeping existing skills only** but not **developmentally continuing to develop skills**. The parents spoke about **how even though their adult children could continue to develop and have the potential to gain**

new skills, there is no service system to support them in skill development. They spoke about how other people continue to develop through employment opportunities and post-secondary education opportunity. Even relationships with others provide opportunities for personal growth as people learn to inter-relate with other people around them. “I truly believe that if he had 10 or 20 years of more intensive speech and occupational therapy he could have been a fluent communicator.” They then discussed that the investment of education ends at 20 years of age but the individual has perhaps 60+ years to live. “15 years to be a fluent communicator – why is that not worth it?”

“The older that these get it doesn’t seem they get the opportunities or recognized because they are grown up. They are no longer a child with a diagnosis. They are forgotten”

“We put a ceiling on services and say that not only you are delayed but after age 18 we are not going to invest any time, energy, or resources in you continuing to grow. This continues to say that our community says there is an injury or blemish that makes our folks not worthy of anything everyone else gets in this world.”

“We put a ceiling on services and say that not only you are delayed but after age 18 we are not going to invest any time, energy, or resources in you continuing to grow. This continues to say that our community says there is an injury or blemish that makes our folks not worthy of anything everyone else gets in this world.” Another individual said, “Once my son turned 18 nothing was about moving him forward just what we could provide. I learn something new everyday why can’t he learn something new everyday.” The group discussed that

individuals with DD are not valued, “there are such low expectations and people who have the level of need that my son has [are not seen as capable] so a lot of people don’t expect him to do things. Finding opportunities is a lot harder because of the judgements and attitudes.” “If we don’t approach the person as a real person with dignity then we are going to just see a lot of behaviors.”

Opportunities to Understand, Learn, and Practice Social Skills

One of the biggest struggles that adults who are considered “high functioning” share is around communication. They have difficulty understanding the variety of social cues needed to get by in the world. People often communicate in generalizations and words can have multiple meanings, so people who interpret communication in a literal way struggle to navigate life in the world socially. A provider might

“I have great insurance and I work full time but under the current system I will never qualify but to me I need a teacher/mentor. ... Especially if I can have support around interpersonal skills.”

say that they will call at a specific time or that they will arrive at a specific time, and when the provider is late it is difficult. One mother who has ASD and also has a child with ASD expressed her frustration managing the provider system that supports her child with ASD: “They just don’t understand that words have meaning and I don’t understand what they are saying. They use words arbitrarily and nuanced and it just doesn’t work. What does work? What I thought would be helpful is writing down how I communicate but they often don’t believe me. My sons support people left because of me because I asked them to come on time – and it was really important and they left. The first day they were late even though I said it really throws me. They didn’t understand why it was important to me.”

The group discussed the desire to be able to self pay for services such as case management but that the option is not available. “I have great insurance and I work full time but under the current system I will never qualify but to me I need a teacher/mentor... Especially if I can have support around interpersonal skills.”

Interaction with Health and Service Systems

For many adults with ASD social anxiety is worsened with interaction as there are many social skills needed to navigate systems with success. For example, many individuals with ASD are rules focused and take things literally, like waiting for someone to call back at a specific time, and when they do not get that call back it may be difficult for them to understand what that means. “I struggle with filling out paperwork and some of that has gotten a lot worse with post office troubles. Then having to make phone calls waiting for people to call me back. It makes things a lot more complicated for emergency dental services because you don’t know if you will get a call back because it is directed to other people.” Another adult stated “Time – people say that they will get back to me on a certain day and they don’t and it really throws me.” A clear nightmare many shared by the self-advocacy group was filling out forms at the doctor’s office and in other settings. When speaking about working with crisis one adult stated “The questions seem so off the wall. Like “Is he in the house?” well does that really matter he is in crises!” Another person agreed and shared their response to “Who do you call in case of an emergency?”: “Well if they don’t know how to call 911! I don’t want to be here.”

“We need a bigger place for parents at the table. Every service provider in the State should have a parent AND a self-advocate in a paid position to provide input.”

Family Input

Overall the parents felt that they had less voice in what their adult children needed than providers and case managers. This was especially true of large provider agencies but not exclusively. “We need a bigger place for parents at

“Family is the lifespan archive of knowledge. Our folks change but they sort of tend to lump all people with disabilities together.”

the table. Every service provider in the State should have a parent AND a self-advocate in a paid position to provide input.” Another mother commented at how frustrated she is when providers take the lead and leave the family out of the conversation. “We have been through many, many diagnostic labels and each time the many many specialists have been positive that they have been the savior to our family and knew what to do – but they were in our life for maybe 10 to 18 months. Family is the lifespan archive of knowledge. Our folks change but they sort of tend to lump all people with disabilities together. My son, and our family have been through many hospitalizations that weren’t necessary because [his behaviors were] extreme but the system didn’t catch his needs.” The system treated the behavior as opposed to understanding what the behavior was trying to communicate.

Dreams

“I am not going to live forever I want to see innovative housing where he doesn’t have to live a life with only people with disabilities and his staff members. He does not feel like he is a member of the disability club”

Many of the parents talked of having a dream to start their own residential facility so that they could earn a living while ensuring their adult child had a full life. One Mom stated that “I am not going to live forever I want to see innovative housing where he doesn’t have to live a life with only people with disabilities and his staff members. He does not feel like he is a member of the disability club – he feels like he is a member of

music and anime group. I want to see affordable housing with people with disabilities and workers who live there and people who are aging and people everyone. Integrated housing where there is still a community of caring and ways to support.”

Another family talked about how their adult child had never spent a night away from home. “My dream is that there is a halfway house” where the adult could have an opportunity to practice staying away from home. The desire was for something more than respite that included skill building and an opportunity to practice skills like staying somewhere else.

Self-Directed Services

A clear dream for one of the guardians is to have the ability to self-direct services with her adult child. “I would have self-direction available with robust budget authority and broker. You wouldn’t need to have a certain level of ability to have access to self-direction.”

Mentorship

Adults with ASD considered “high functioning” spoke about having a mentor as a dream service. This looked different for different people but largely involve receiving help with either social interpretation or executive functioning. For one person: “I need help catching up as a result of not being able to process in a way that worked. I missed out on a lot of my education. For me it would look like a tutor. What I need – I have tools that I have found online – but one of the biggest challenges is that I need someone to help with me focus and set up a plan. Someone that I can meet every day and can keep me on track and hold me accountable. I am a father with two children and a step son and I work a full time on – I need a mentor. I haven’t been able to talk with anyone about my deficiencies. I would love to learn more about my deficiencies and get better in my deficiencies. I would like a teacher / a mentor. When I got my diagnosis they said here is where you need help – have a nice day.” Another individual desired someone they could call every now and then to ask questions. “I’ve just always wanted a place to ask questions like ‘How do I get a new dishwasher??’ Things that I have never done but have to do. I want someone a place to ask how do I do this. Even if it wasn’t a mentor but a place I could call to ask question. So, an on-call mentor.”

Opportunities to Socialize with others who have ASD

Another dream that people with ASD expressed was a desire to have social opportunities in which they can meet and talk with other people with ASD. Some have found that online, “I am also on a gaming board called neuro-diverse gaming. Their whole mission is to stream and build community gaming online.” “A lot of us have been told how we have to act and do and that is really difficult to be able to practice how to act and do that. Taking a pottery class, gaming console – we can’t afford it and we don’t have the support – instead we are spending all our money on medication to keep us whole. It would also be nice to have some sensory support for deep pressure”

“A lot of us have been told how we have to act and do and that is really difficult to be able to practice how to act and do that.”

DSS Connecticut ASD Waiver²

One discussion that the Adult “High Functioning” group had involved access to a service like Connecticut’s Autism Waiver. This waiver provides supports to adults with ASD who do not have an intellectual disability yet have at least two functional limitations of daily life. Services are capped at \$50,000 annually per participant and include a wide array of services including;

- Clinical Behavioral Supports
- Social Skills Group
- Job Coaching
- Life Skills Coach
- Community Mentor
- Individual Goods and Services
- Personal Emergency Response System
- Respite
- Assistive Technology
- Interpreter
- Non-Medical Transportation
- Specialized Driving Assessment
- Live-in Companion

² <https://portal.ct.gov/DSS/Health-And-Home-Care/Autism-Spectrum-Disorder---ASD/Autism-Spectrum-Disorder---ASD>