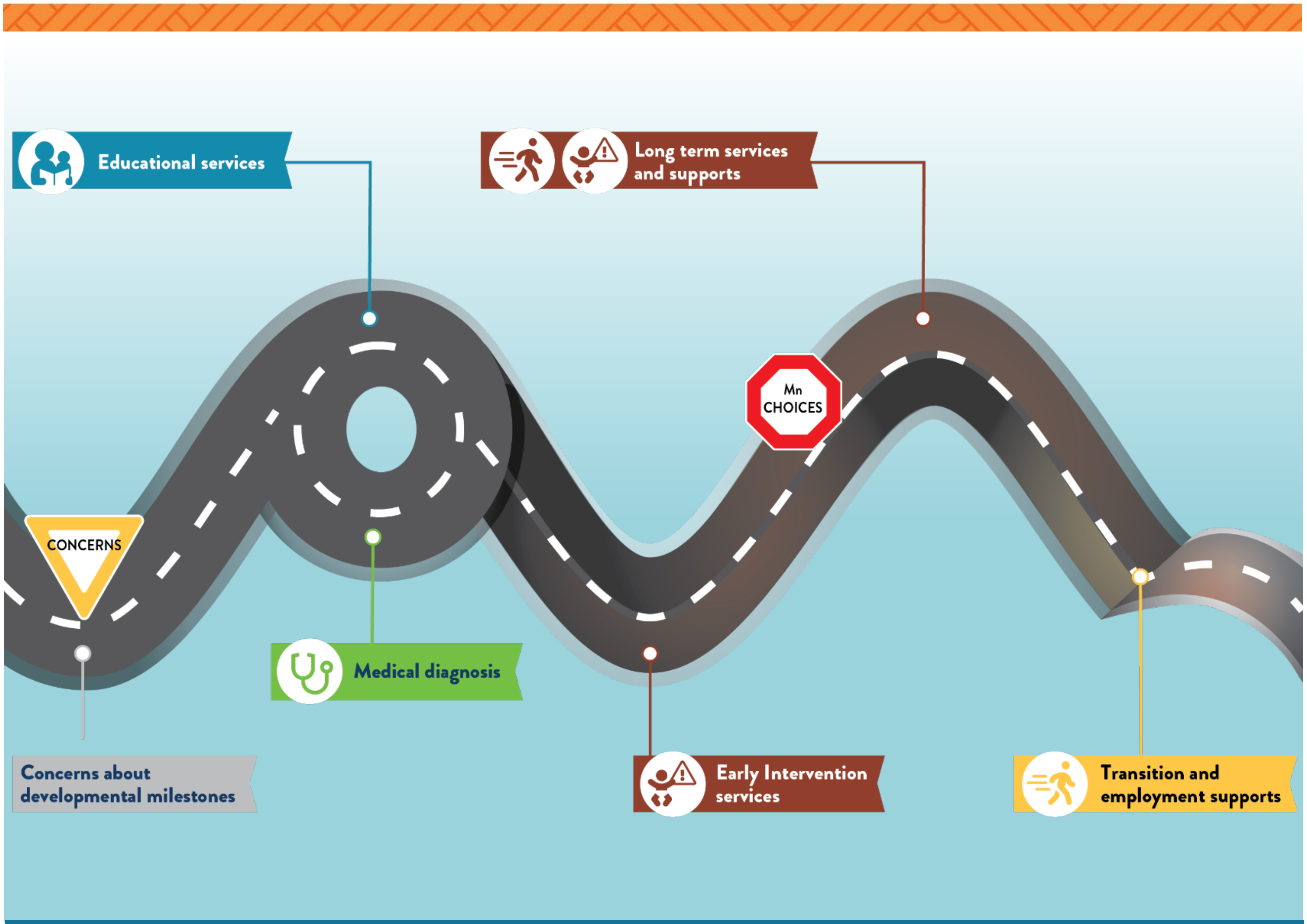
Mapping the Journey of Families Who Have Children with Autism Through Social and Human Services, Medical, and Education Systems

DECEMBER 2020



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Introduction

There are a variety of services and supports in Minnesota for children and youth with autism who are age 0-21. These include services and supports provided by state agencies, including the Minnesota Department of Human Services, Minnesota Department of Education, Minnesota Department of Health, and the Minnesota Department of Employment and Economic Development. They are also provided by an array of nonprofit organizations, community groups, hospitals and clinics, schools, and autism centers that provide therapy for children with autism.

This report describes the results of a Journey Mapping process Wilder Research conducted on behalf of the Minnesota Department of Human Services (referred to as the Department of Human Services or DHS throughout this report) to learn more about the experiences of families as they navigate this system. We aimed for this study to encompass a wide variety of perspectives and included underserved demographic groups, so we reached out to families in the Twin Cities and greater Minnesota, as well as families who speak Hmong, Somali, Oromo, and Spanish as a primary language and American Indian families.

This Journey Mapping process was a component of a larger evaluation Wilder Research was contracted to conduct of the Department of Human Services' Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit. The EIDBI evaluation has been guided in part by a Learning Collaborative. This is a group of experts in the field, including autism researchers and academics, therapy providers, and those working within the special education field. Wilder Research worked with staff at the Department of Human Services to develop an initial Key Systems Touchpoints document, which outlines the different system areas families of children with autism can and do encounter. This document was intended to be a common reference for Wilder Research, the Department of Human Services, the Learning Collaborative, and study respondents during this Journey Mapping effort. This Key Systems Touchpoints document serves as the foundation for this report, as well; this can be found in the Appendix. We understand that families move through the system in varied ways and that they will not necessarily have experienced all points outlined in this project or in the way that we have outlined them.

What is a journey map?

A journey map is a visual depiction of the path that individuals take as they navigate a system. The map outlines system touchpoints (encounters) and the positive experiences as well as areas for improvement based on feedback from system users. Staff at the Minnesota Department of Human Services, as well as professionals working throughout the system who served on a Learning Collaborative that advised our evaluation, defined a series of touchpoints for families with children with autism to interact with the systems that serve them. From there, Wilder Research conducted interviews with parents about their experiences with the system. With that information, we were able to create a visual map of family's experiences as they navigate the system.

For more information about journey mapping, see this blog post from FSG: Systems Thinking Tool: Journey Mapping
https://www.fsg.org/blog/systems-thinking-tool-journey-mapping

A note about terminology

It is common in this field to refer to those with autism as being "high functioning" or "low functioning." This serves as a shorthand for indicating the level of severity of the person's autism. However, the terminology is often unhelpful and can be harmful; the term "low functioning" can add to stigma around an autism diagnosis, and the term "high functioning" can imply that these people with autism do not need supports.

In recent years, more advocates and professionals working within the system have been encouraging the adoption of different terminology. Unfortunately, advocates and professionals do not have consistently agreed upon terms to use in place of these. Throughout this report, we attempt to avoid the phrases "high functioning" and "low functioning" and instead clarify some of the nuances respondents were attempting to provide with these terms, such as "autism with/out intellectual disability."

Methods

In April and May 2020, we interviewed nine professionals (referred to as “stakeholders” throughout this report) who work in various parts of the system to gather their perspectives about the easiest and most challenging parts of the system for families to navigate. With the help of the Department of Human Services and their partners, we also recruited 83 parents and caregivers of children with autism to participate in one-on-one interviews. These interviews focused on the experiences these families have had through all parts of the system that they have encountered, including high points and low points in their experiences. Respondents also provided an overall rating based on their experiences for each of the key touchpoints. A numerical value was assigned to each rating: Excellent (5), Good (4), Fair (3), Poor (2), and Terrible (1). The ratings were added together to calculate an average overall rating for each touchpoint or “phase.” Some respondents had more than one child on the autism spectrum. For these families, we asked that they provide an overall rating for each phase that took into account all experiences they had with all of their children on the spectrum.

We had initially planned to conduct focus groups with parents of children with autism, in alignment with the standard journey mapping methodology. However, the COVID-19 pandemic prevented our ability to convene groups of people together. Because of this, we shifted all data collection to phone-based interviews. The pandemic added a layer of difficulty in reaching parents who speak a language other than English at home; while we intended to partner with community organizations to access culturally-specific support groups for parents of children with autism, we were not able to do so in accordance with social distancing guidelines.

Notes and transcripts from the interviews with parents and caregivers of children with autism were coded using Atlas.ti. The evaluation team developed a codebook after becoming familiar with key themes that families spoke about during the interviews. The evaluation team established interrater reliability before beginning analysis in full; two members of the team coded the same interview and compared codes upon completion, discussing the areas in their analysis that did not align completely and coming to agreement on the interpretation of codes. After the analysis team completed coding, we examined which codes were most common by phase of the system and by the questions that address the system as a whole, as grouped in the report below. This process was also used to understand how key themes were similar or dissimilar based on the child’s demographic characteristics, including age, geography, gender, and race/ethnicity. Interview protocols and the codebook used for analysis can be found in the Appendix.

About this report

This report provides a summary of what we learned from a wide array of parents of children with autism and system stakeholders. In this report, we present overarching themes, families’ experiences in each phase of the system, and parents’ reflections of their experiences with the system overall.

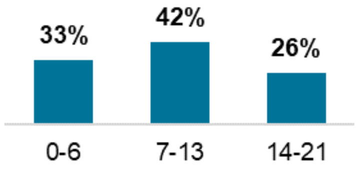
We aim to shed light on the experiences families have as they encounter the system of services and supports for children with autism in Minnesota. The Minnesota Department of Human Services and their interagency autism team are a primary audience for this report, as they may use this information to make changes to the system to improve the experience of families. Families of a child with autism may also use this report as a guide for what services and supports are available to them and to learn more about how other families have experienced those services and supports. We also hope that this report will be useful for advocacy organizations as they work to improve the experiences for families of children with autism; they may use our findings to validate what they already know are challenges for families and to better understand other components of the system with which they work less frequently. Advocacy organizations could also use the findings of this report to support the work they do with funders and other stakeholders.

Participant demographics

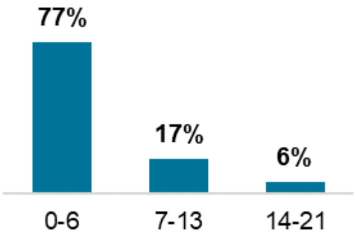
Eighty-three parents participated in our interviews. We asked respondents demographic questions about themselves and their children with autism. We received demographic information for 89 children.

Children’s current age was fairly evenly spread across three groups: 0-6, 7-13, and 14-21 (Figure 1). Just over three in four of these children were diagnosed with autism before age 6 (77%; Figure 2).

1. Child's current age (N=89)

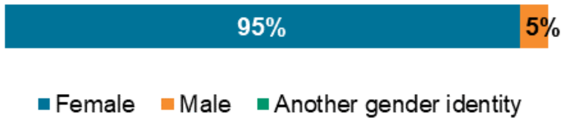


2. Child's age at diagnosis (N=86)

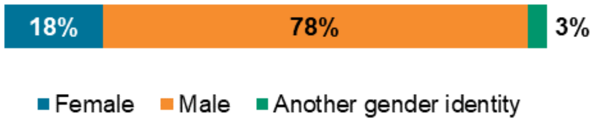


The vast majority of respondents identified as female (95%), while their child(ren) with autism were most commonly male (78%; Figures 3 and 4).

3. Parent gender (N=83)

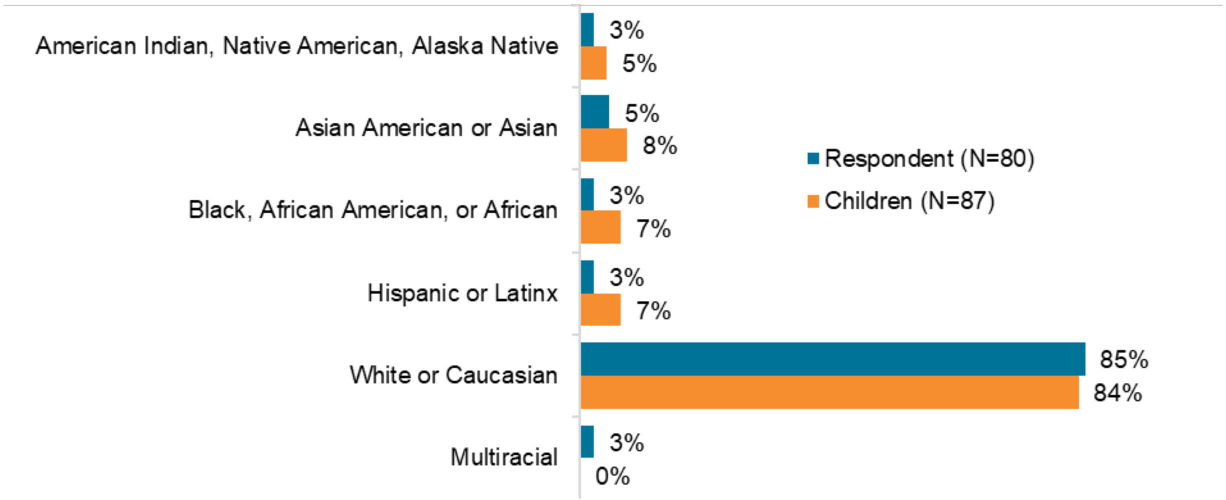


4. Child gender (N=88)



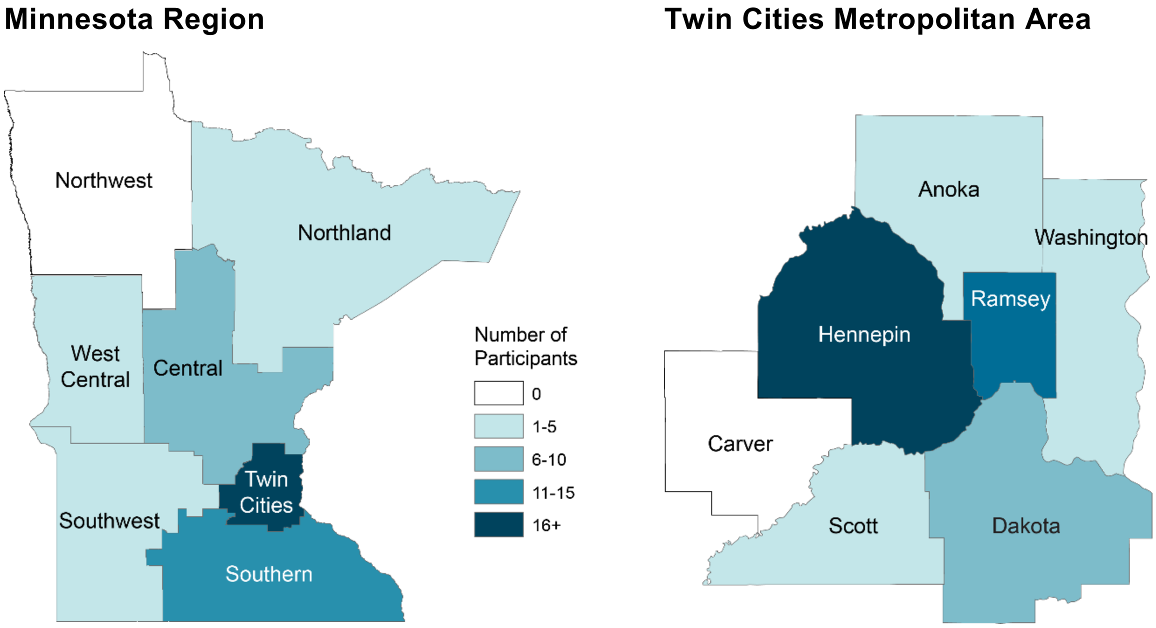
We asked respondents to indicate their racial/ethnic identity, as well as the racial/ethnic identity of their child or children who are on the spectrum. Respondents could select multiple racial/ethnic categories. Respondents and their children were predominately white (85% and 84%, respectively; Figure 5).

5. Race of respondents and children



Sixty-three percent of respondents lived in the Twin Cities metro area and 35% lived in greater Minnesota. The geographic location of respondents can be seen in the maps below.

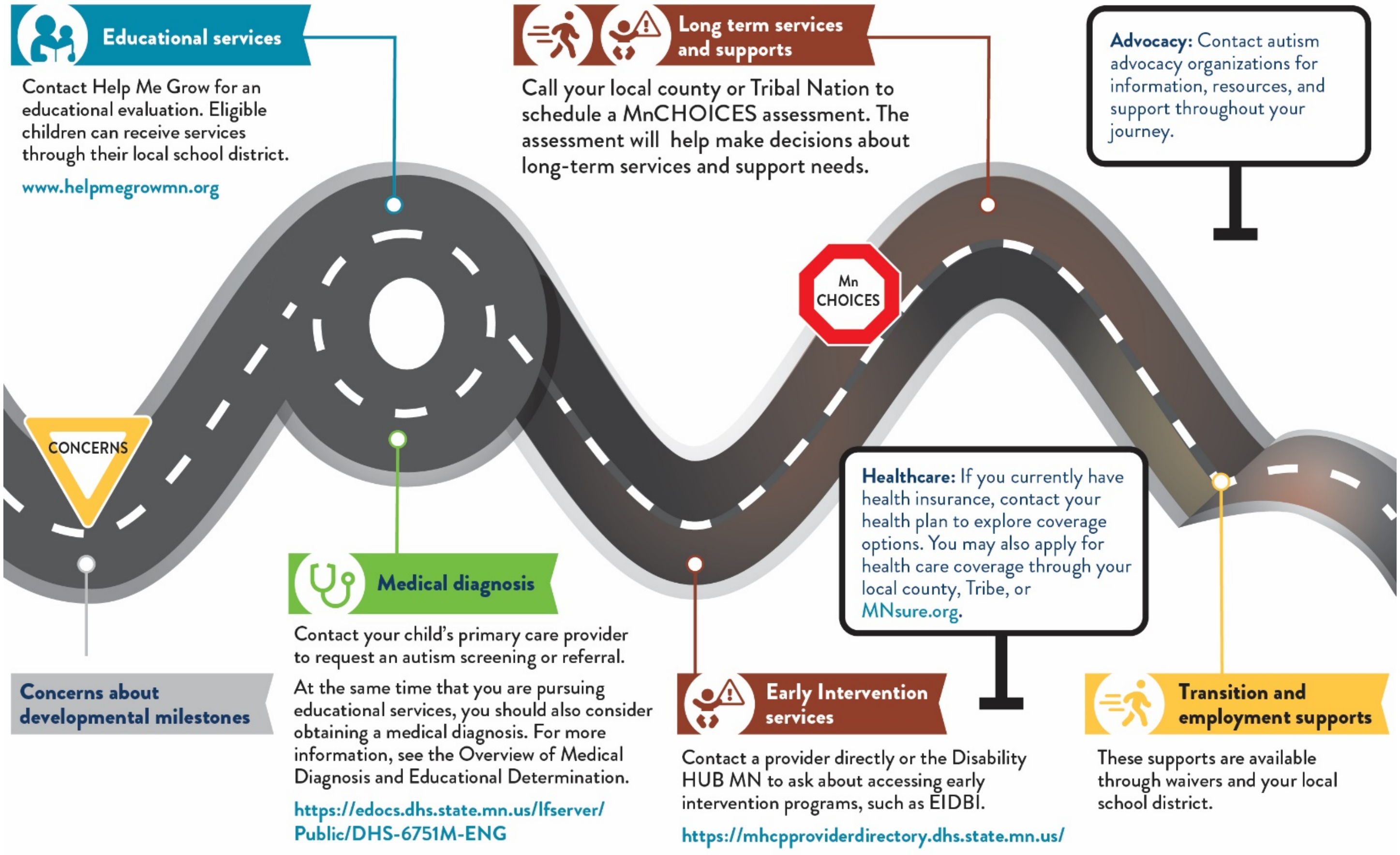
6. EIDBI Family Interview Participation



Additional resources about autism and related services and supports in Minnesota:

- Pathway to Services and Supports for Autism Spectrum Disorder (ASD)
- Minnesota Autism Resource Portal
- EIDBI benefit overview
- CTSS benefit overview
- EIDBI 101 training for potential providers
- EIDBI 101 training for families of children with autism
- Advocacy organizations, including The Arc, Autism Society of Minnesota (AUSM), Parent Advocacy Coalition for Educational Rights (PACER), Family Voices, and the Minnesota Disability Law Center

7. Journey map



Concerns about developmental milestones

Medical diagnosis

Contact your child's primary care provider to request an autism screening or referral.

At the same time that you are pursuing educational services, you should also consider obtaining a medical diagnosis. For more information, see the Overview of Medical Diagnosis and Educational Determination.

https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6751M-ENG

Educational services

Contact Help Me Grow for an educational evaluation. Eligible children can receive services through their local school district.

www.helpmegrowmn.org

Early Intervention services

Contact a provider directly or the Disability HUB MN to ask about accessing early intervention programs, such as EIDBI.

https://mhcpproviderdirectory.dhs.state.mn.us/

Long term services and supports

Call your local county or Tribal Nation to schedule a MnCHOICES assessment. The assessment will help make decisions about long-term services and support needs.

Healthcare: If you currently have health insurance, contact your health plan to explore coverage options. You may also apply for health care coverage through your local county, Tribe, or MNsure.org.

Transition and employment supports

These supports are available through waivers and your local school district.

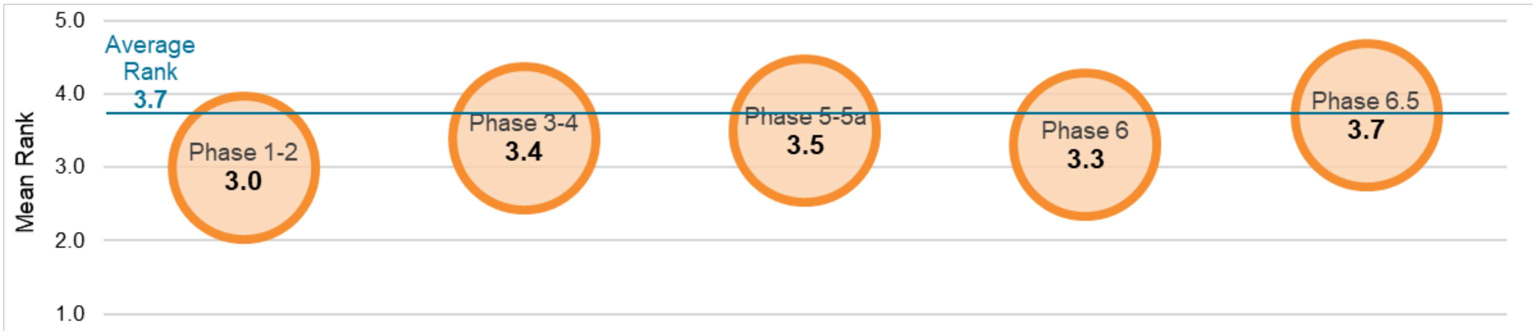
Advocacy: Contact autism advocacy organizations for information, resources, and support throughout your journey.

For more information, see **mn.gov/autism** and the Pathway to Services and Supports for Autism Spectrum Disorder (ASD) **https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6751-ENG**

The Journey of Families who have children on the autism spectrum

PHASE 1-2	PHASE 3-4	PHASE 5	PHASE 6	PHASE 6.5
Awareness and Questions on Developmental Milestones	**Medical Diagnosis and Initial Screening and Assessment**	**Educational Identification and Services**	**Health Insurance**	**Case Management Services**

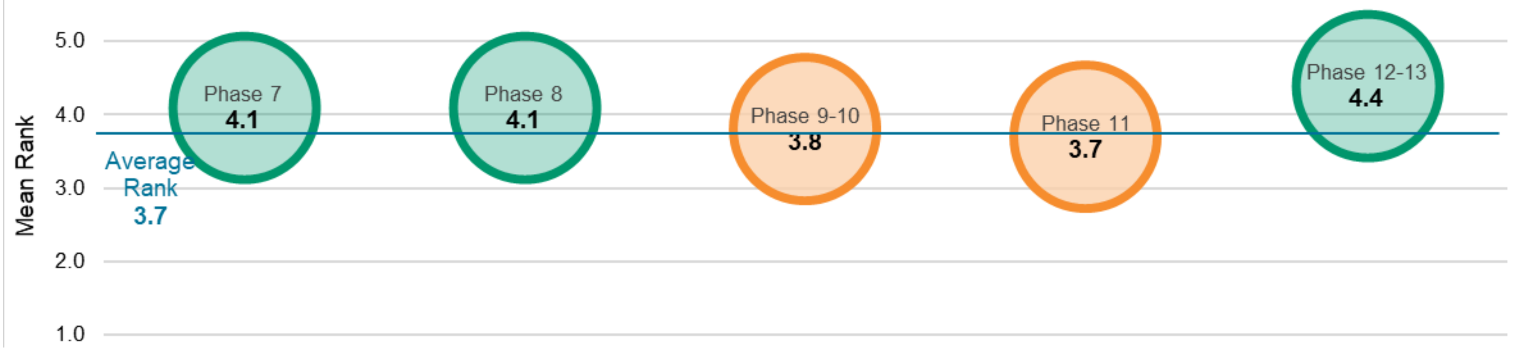
Experiences



Note: Excellent = 5, Good = 4, Fair = 3, Poor = 2, and Terrible = 1

	Phase 1-2	Phase 3-4	Phase 5	Phase 6	Phase 6.5
Positives	- Parents received support and information from family, friends, and other informal networks. - Professionals, especially pediatricians and primary care doctors, took questions seriously and helped them move forward with screening and assessment.	-Thorough evaluations give parents the information they need to feel confident about moving forward. -Clinics that provide guidance and support on next steps relieve anxiety from parents.	- School staff, especially those working directly with children and families, can be very supportive and help with overall system navigation. - Person-centered school supports improve quality of life for families.	- Affordability of services is one of the most important things for parents; they are able to choose the services their child needs rather than the services they can afford. - Parents who are on Medical Assistance are particularly positive about their experiences.	- Case managers can provide guidance on services and supports to pursue, effectively helping with system navigation. - Case managers can serve as effective co-advocates with parents. - Case managers give parents one person to call when they have questions.
Areas to improve	-“Wait and see” guidance from professionals and personal networks can prevent a child from receiving earlier diagnosis. - Parents feel anxious as they do not know how to best help their child, or even blame themselves for atypical development.	- Children that present outside of what is considered to be the “norm” face difficulty in getting a diagnosis. - Parents feel overwhelmed upon receiving their child’s diagnosis of autism. - Wait lists keep families from getting a diagnosis promptly. - Parents do not receive enough guidance on what to do next.	- Parents report having to “fight” to get their child an IEP. - School and district administrators push back on families and are hesitant to establish robust school-based supports. - School resources vary radically by district. - Autistic children without intellectual disability often feel overlooked by schools.	- Parents often do not know that they should explore MA or TEFRA. - Services can be prohibitively expensive for families just on private insurance. - Paperwork is confusing and overwhelming. - TEFRA fees can be too expensive for families. - Parents struggle to have questions answered.	- Families do not know what types of case management services are available or what case management can and should do for them. - Case managers are often overloaded with families to help; this hurts the level of service they can provide. - Parents reported difficulty in getting helpful information and guidance from case managers.

Experiences



Note: Excellent = 5, Good = 4, Fair = 3, Poor = 2, and Terrible = 1

	PHASE 7 **Early Intensive Services**	PHASE 8 **Continued Supports Accessed through a Hospital or Clinic**	PHASE 9-10 **MNChoices Assessment, Waivers, and Other Supports**	PHASE 11 **Transition Services**	PHASE 12-13 **Services and support from other organizations and resources**
Positives	- Therapy can vastly improve quality of life for families as children's outcomes improve. - Families forge strong relationships with therapists at autism centers. - Therapists provide a wide range of information and resources to parents.	- Services and supports can make a big difference in child outcomes, improving the quality of life for the child and their family. - Professionals in this phase often serve as advocates for the family, going beyond what is expected of them to help families navigate the system and receive the services their child needs.	- Waiver services open up a world of opportunities for families, providing financial stability for parents to stay home and covering the cost of equipment and services that are necessary for a reasonable quality of life. - The MNChoices assessment is often easy for parents, and assessors often provide helpful information.	- Personal Care Assistants (PCAs) can improve the quality of life for parents as they assist with the day-to-day caretaking responsibilities for their child. - Transition services give parents hope that their child will be able to live a meaningful life with some level of independence.	- Social media is a common space that parents of children with autism use for information, resources, and support from other parents. - Advocacy organizations provide helpful information and resources to families, and even serve as co-advocates in certain situations.
Areas to improve	- Waitlists prevent children from getting care as soon as they have a diagnosis of autism. - Some parents expressed concern about Applied Behavior Analysis (ABA) therapy, the most common therapeutic approach used in early intensive services.	- Provider shortages make accessing services difficult. Waitlists can be long, and families – especially those in greater Minnesota – must drive long distances to access services. - Finding a provider who is a "right fit" can be difficult, especially for teenagers with autism.	- Parents must have the "right" words to be able to access waiver services; parents are not offered waiver services, but must learn how to access them from other parents who have successfully done so. - Paperwork is confusing and overwhelming, and county staff are rarely available to offer assistance. - Parents need more guidance on how to build budgets to appropriately use the waiver funds they are eligible for.	- Parents are unfamiliar with what services and supports are available to their child as they transition into adulthood. - Provider shortages are a challenge; parents particularly noted challenges in accessing PCA services. - Parents are not approached with consistent information about these services and supports and typically rely on other parents for information.	- While some parents are very well connected to different organizations that can provide support, others were unaware of their existence. There is a sharp divide in the types of resources parents are connected to. - Scheduling can be a challenge as parents try to access different meetings and informational sessions while balancing work and caregiving responsibilities. - Social media can spread misinformation about autism

PHASE 1-2: AWARENESS AND QUESTIONS ON DEVELOPMENTAL MILESTONES

Phase 1-2
3.0

Key touchpoints

Families start their journey of having a child with autism by being aware of developmental milestones their child should be meeting and having questions or concerns about whether or not their child is progressing typically.A strong research base shows that early diagnosis and intervention is incredibly important in improving outcomes for children on the autism spectrum (Remington et al., 2007).

- Families can experience the following interactions with the system:
- Parent or caregiver, health care provider, or school staff identified a need for autism evaluation or additional screening
- Referral for additional assessment, evaluation, or screening

Positive experiences

Families discussed some positive experiences they had during this phase.

- Some parents had great experiences with qualified professionals who helped them feel validated that something was not typical with their child's development and supported them in pursuing the next steps of getting a medical diagnosis and/or educational identification of autism.

  > *"Once we did get into speech therapy, we got more guidance with heading down the autism [services] path. Our speech therapist was the one that helped guide us to get to an autism diagnosis."*

- Parents frequently turned to their closest networks during this phase for information, resources, or validation. Parents who are connected to networks of those who are knowledgeable of the system or of the signs and symptoms of autism had more positive experiences than those parents who have networks that lacked awareness or cast aside concerns, as detailed below. In our interviews, well-connected parents spoke about the ways in which they feel privileged to have the time and resources to be well-connected. Parents commonly spoke about being thankful that they speak English as a first language, were well-educated, and knew people who were professionals working in a related field. They often discussed how difficult it must be for people who do not speak English fluently, don't have financial resources, and don't have a wide network of friends and family to start the journey to get services and supports.

Areas to improve

Some families experienced obstacles or challenges in the "identification" phase.

- Parents and other family members are often in denial that anything seems wrong or that the child may be developing atypically. Denial was most prevalent in this first phase; receiving validating information and feedback from professionals almost always quashed denial, which most commonly affected close family and friends of the child with autism. We learned of many cases in which one parent was in denial about atypical development of their child. Grandparents and close friends of parents were also likely to brush off concerns from parents, recommending that parents "wait and see" and that their child will develop typically over time, which many parents noted was likely an attempt to assuage fears. While those close to the family may be inclined to deny any concerns about the child in an attempt to reduce stress on parents in the short term, parents often spoke of this as being an incredibly detrimental experience. They turned to blaming themselves and their own parenting for developmental delays or felt guilty later in their child's life that they didn't seek a diagnosis earlier.

- Doctors and other professionals that families interact with in these early stages will also often give "wait and see" guidance to families. While many parents want to hear that their child is developing typically and that things will work out, in hindsight parents often feel regret that they were not able to get their child a diagnosis and services as soon as possible because of recommendations from doctors and other professionals to wait.
- Pediatricians and primary care doctors can face difficulties in diagnosing autism in cases where children are not meeting developmental milestones but may not exhibit some of the stereotypical signs of autism.
- Specialists look for answers to children's health issues within their own specialty; because of this, a child may receive a variety of misdiagnoses before they are able to reach the diagnosis of autism, which ultimately helps to explain the variety of symptoms together to one underlying health issue.

> *"First and foremost, is just knowing that she had global delays and figuring out what's going on, and not being able to pinpoint exactly whom to approach. Our primary care provider should have been more on top of it. Our primary care provider just directed us to so many other specialties, we went to a neurologist, geneticist, feeding issues, so many others… that took three years."*

- Children with autism are sometimes labeled as bad, difficult, or troublesome based on the types of signs and symptoms of autism they display. This can be a traumatic experience for families as they interact with the world around them. Parents also discussed ways in which they believed extended family members, friends, and strangers labeled them as "bad parents."

> *"It was just constant. 'He's just a brat. You're not being a good parent.' That's what we were hearing all the time."*

Considerations

Given the experiences of families and stakeholders in this phase of the system, we offer the following issues to consider.

- This initial phase is a time of high anxiety for parents. Parents experience worry about their child developing atypically, but do not yet have the answers that a diagnosis can provide.
- Parents are confused about what to do when their child has been developing typically but then regresses on basic skills. Public awareness campaigns should include a note that a child may not meet these developmental milestones or may regress after having met them; in both scenarios, parents should seek further assessment.

- Professionals of various sorts seem to be hesitant to proactively encourage parents to consider whether or not they should get their child screened for autism; instead, it seems that they wait for a parent to bring it up and then confirm those feelings/thoughts. This can be particularly challenging for first-time parents who are less familiar with what developmental milestones look like and when their child should be hitting them. More training, information, and resources for professionals who work with children in the general population could assist with early identification and diagnosis. Training, information, and resources for these professionals could also provide guidance on how to have these difficult conversations with parents in a productive way.
- Children who are born to parents who have already had one or more children benefit from their parents' awareness of developmental milestones.

> *"I think part of the reason he wasn't caught right away was that he's our first kid, I didn't know what he was doing. Looking back, I thought he was pointing when he was just holding his hand up… I'd been at a New Year's Eve party with another kid the same age as [my son] and I realized how different they were. So I went back to the [ASQR Developmental Milestones] sheet and we went through that together and realized he had a lot of these signs."*

PHASE 3-4: MEDICAL DIAGNOSIS AND INITIAL SCREENING AND ASSESSMENT

Key touchpoints

Phase 3-4
3.4

After receiving a referral, the family will then meet with a team of medical professionals to review a detailed developmental history of the child and perform a diagnostic assessment and/or comprehensive multi-disciplinary evaluation. This is an in-depth assessment of a child's development to inform health care professionals of whether or not a diagnosis of autism is appropriate for the child (Centers for Disease Control and Prevention, 2020). A diagnosis of autism is required to access many benefits and services, and differs from an educational identification. Autism can be diagnosed as early as 18 months, though the current average diagnosis age in Minnesota is four years and eight months old (Minnesota Autism Developmental Disabilities Monitoring Network, 2020). The United States has improved over time in diagnosing children at a younger age. As noted above, the average age of diagnosis for the youth at the center of this study is about five years old.

The key touchpoints listed here are the beginning of the many interactions that families will have with the medical field as they navigate their journey:

- Parents or caregivers make an appointment with their primary care doctor
- Primary care doctor takes the child's developmental history and completes exams and screening
- Primary care doctor refers the child and their parents or caregivers to psychology, developmental pediatrics, and/or another specialist for diagnostic assessment
- Diagnostic assessment and/or comprehensive multi-disciplinary evaluation (CMDE) is completed
- Health care provider calculates the results and scores the assessment and communicates the results to the family

It is important for families to consider pursuing both a medical diagnosis and educational determination of autism to be able to access the full range of services and supports that could help their child. For more information about the differences between a medical diagnosis and educational determination of autism, see this Overview of Medical Identification and Educational Determination of Autism Spectrum Disorder.

Positive experiences

During this phase of the journey, families identified the following experiences as positive.

- Multi-disciplinary evaluations are helpful, comforting, and informative for parents. After these assessments, parents reported feeling knowledgeable about the challenges their child is facing and often felt validated that professionals agreed with their concerns about their child.
- Parents appreciate meetings that are dedicated to thoroughly going over results, with opportunities for them to ask questions of the diagnosing health care provider. Parents said they especially appreciate when their child's health care provider gives detailed and specific recommendations and referrals as next steps. Concrete next steps can make parents feel less overwhelmed, and helps them feel more in control of their family's situation.

- Supportive, person-centered, and respectful primary care doctors or pediatricians and assessment teams make a world of difference. While the assessment process must inherently assess weaknesses of the child's development, also highlighting the child's strengths and providing tips to parents about how to use those strengths for development can make the process much more encouraging for parents.
- Some clinics in which a child is diagnosed with autism have teams of professionals to provide information, resources, and guidance on next steps for families. Families who were supported by these teams were very positive about their experiences.
- Parents often feel relief to have a diagnosis attached to what they have known to be true, a point to start from, and research they can do.

> *"We finally had some answers about what was going on. At this time, we were having issues. I was struggling with what people were telling me what to do, how to parent him. You know, everyone has an opinion…The diagnosis helped me psychologically to be able to parent better."*

Areas to improve

Families discussed numerous obstacles to getting appropriate screening and assessment for their child and in getting a medical diagnosis of autism.

- Issues with waitlists were most frequently reported in this phase; parents must face long wait times to get their child an appointment for the assessment that results in a medical diagnosis, which is required to get access to the wide array of services and supports. Parents noted the stress of being aware that early diagnosis and intervention is critical but being forced to wait to get a diagnosis.

> *"We knew a year before he got the evaluation that he was on the spectrum. That was just off of us Googling 'autism.' It was just so very obvious. It wasn't mild at all. I didn't know anything about autism. The most frustrating part was waiting for the evaluation, for a professional team to tell us what was obvious to everyone… we couldn't get the supports in place because we didn't have the document showing his diagnosis."*

- Pediatricians and primary care doctors have inconsistent training and messaging. As mentioned in the previous section, this results in a lot of "wait and see" suggestions and misdiagnosis for children with autism.
- Pediatricians and primary care doctors can be dismissive of parental concerns, generally not listen to parents, or blame parents for their child's behavior problems.

> *"We brought up specific issues with the doctor – no eye contact, going backward with different skills, not speaking… When I told this to the doctor, he said 'how hard have you tried to get him to look you in the eye?' 'Are you giving him enough time and attention?' I left feeling way worse than ever before. I questioned my parenting. I was wondering if I wasn't giving him what I've given [my] other kids. It was really horrible. My husband and I went down a path of 'what am I doing wrong? What could I be doing better?"*

- Parents are often overwhelmed at the diagnosis. Parents were very positive about receiving written materials explaining the diagnosis in layman's terms and some clear direction on what to do next.

> *"It's extremely overwhelming because anytime you go to the doctor and they give you information, you a lot of the time only hear half of what they're saying… first you're absorbing the information as it pertains to you or your family member, and then you have to remember what it is they're saying intellectually as you're processing it emotionally. It's good to have things written down in a report with recommendations; people need to be able to go home, think about it, and then go back and process that again."*

- As mentioned in the previous section, pediatricians and primary care doctors have a difficult time diagnosing what doesn't present as the version of autism that is in their minds.

> *"Socially, he's always been pretty good, which is why I think it was hard for us to get the initial diagnosis."*

- Parents of girls mentioned their struggles to get their daughter a diagnosis. In particular, autistic girls without intellectual disability are better able to hide signs and symptoms of autism because of coaching in social expectations, according to parents. Additionally, autism is widely viewed as a "boy's thing" so doctors are less likely to think to pursue an autism diagnosis for girls.
- Autistic children without an intellectual disability can face difficulties in getting a diagnosis. Not having an intellectual disability can both keep kids from looking like the "typical" child with autism, and these children may also learn how to mask their symptoms or answer the assessment questions "correctly."
- Shortages of providers who can diagnose autism can prevent children from getting diagnoses promptly. Relatedly, distance to and wait times for providers who can diagnose autism burdens families with costs and lost time.

> *"To get a thorough assessment done, I had to go down to St. Joseph, which is over three hours away. And it was a two-day thing, and so that meant, of course, staying overnight. And since both appointments were in the morning…the best thing was to go down the night before. So you figure you're paying for two nights in a motel, then eating out, and just travel expenses in general. So that's a kind of a barrier. To get a good quality assessment, I had to go over three hours away to do it."*

STAKEHOLDER FEEDBACK

We spoke with professionals involved in the medical diagnosis touchpoint. When the system works well, stakeholders mentioned the following positive aspects:

- Tailored, individualized recommendations based on a child's strengths and difficulties, as determined by the assessment.
- Vast knowledge of the varieties of therapeutic supports available for a family and clear explanation of the pros and cons of each approach.
- Immediate connection with a social worker who will guide and support the family after they have gotten the diagnosis.

Challenges include:

- Poor coordination across parts of the system that families interact with.
- A lack of awareness among primary care doctors and pediatricians of the signs and symptoms of autism, the importance of getting a diagnosis right away, and the kinds of therapeutic supports that are available for children with autism.
- Provider shortages.
- A lack of:
    - mental health supports for parents of children who are receiving a diagnosis of autism.
    - navigation assistance, especially for families that speak a language other than English.
    - translation assistance throughout this phase.

Considerations

Given the experiences and feedback from families, we offer the following issues to consider related to this phase of the journey.

- Common resources would be helpful for families. Some specific examples that parents provided are:
    - A document to be given to families before the assessment that describes what will happen during the assessment and why it is important
    - A document to be given to families before the assessment that describes "myths vs. facts" about autism
    - The full results of the diagnostic assessment in writing for parents to review in depth on their own time
    - A document to be given to families after the assessment has been completed that describes different types of services and supports their child could access, including the pros and cons of each and how to access those services in their community or geographic region
- Providers had differing levels of knowledge and expertise in autism, even including those doing the diagnostic assessment. Providers that are doing the "gold standard" in this phase should be used as examples, and other providers should be given the training and resources to emulate this level of care for families of children with autism.
- Parents also recommended there be a follow-up appointment about a month after the diagnosis to review any questions parents may have after they have had a chance to digest the news of the diagnosis, do their own research, and formulate questions that should be addressed by a professional.

> *"The stuff that was printed with the evaluation would have been a blur at the time for me to look at. Having someone at the clinic setting that's there specifically to help you navigate what's next after you have had time to process, that'd be helpful."*

- The testing process can be discouraging and traumatic for families. Tests are long, force the child to "fail" in a variety of ways, and can cause the child to "melt down." Stakeholders should consider ways to make this process more encouraging for families and offer more mental health supports for the entire family unit during this phase.
- Pediatricians and primary care doctors could benefit from greater collaboration with specialists. Children who see a variety of specialists may receive a wide variety of different diagnoses to describe the ways autism is presenting itself in the child rather than one diagnosis of autism. Greater collaboration and communication across providers, as well as increased training for all types of health care providers about the signs and symptoms of autism, could prevent some of these misdiagnoses.
- Parents of children who were diagnosed a long time ago mentioned that things have gotten better since they went through their child's diagnosis. They discussed how medical professionals and the general public have a better understanding of autism, which makes these groups better equipped to refer children for screening and assessment and discourages "wait and see" recommendations for parents. The Department of Human Services and other state agencies should continue their efforts to increase understanding, because it does appear that the increased knowledge/awareness is leading to better diagnosis experiences for families of kids with autism.
- The Department of Human Services should work across state agencies and with the legislature to address provider shortages that prevent families from receiving a diagnosis promptly upon identifying signs of autism.

PHASE 5: EDUCATIONAL IDENTIFICATION AND SERVICES

Key touchpoints

Phase 5-5a
3.5

Schools can provide a wide variety of services and supports to help children with autism be successful. In order to access these services and supports, a child must have an educational determination of autism. For educational determinations of autism, educators use a version of the medical screening tools that is also informed by educational needs and the child’s educational environment. As mentioned above, an educational determination of autism is different than a medical diagnosis; a medical diagnosis by itself will not grant access to educational services.

Two important documents families of children with autism should know about are Individualized Education Plans (IEPs) and 504 plans. 504 plans describe accommodations the school will make to assist a child with special needs in their learning and educational progress. IEPs are more detailed; they provide a concrete plan for students who need special education services. IEPs are made by a team of school staff and the child’s parent as a result of a comprehensive evaluation within a school. IEPs are legally binding for the school. Parents should explore these two options and determine which is right for their family.

It is important for families to consider pursuing both a medical diagnosis and educational determination of autism to be able to access the full spectrum of services and supports that could help their child. For more information about the differences between a medical diagnosis and educational determination of autism, see this Overview of Medical Identification and Educational Determination of Autism Spectrum Disorder.

Key touchpoints at this phase in a family’s journey include:

- A parent, caregiver, and/or school staff request a special education evaluation
- A parent or caregiver gives consent for evaluation
- Assessment is completed by a school professional and results are communicated to the family
- An IEP or 504 plan is developed and implemented

Education services include:

- Community education resources, like Help Me Grow, Early Childhood Family Education (ECFE) program, and Head Start
- Special education during preschool, including Individual Family Service Plans (IFSP), Early Childhood Special Education (ECSE), Individualized Education Plans (IEP), and services provided with a school or community-based preschool
- Special education during K-12, including special education services like assistive technology, direct instruction in core areas, and home visits

Positive experiences

Families discussed positive experiences in getting an educational determination of autism and accessing services through the school, as discussed below.

- Schools with the resources to support children with autism and their families can provide incredibly positive experiences for these families. School resources that parents found helpful include staff who are knowledgeable of or specialized in working with children with autism and physical tools and resources like sensory-friendly rooms.
- Some school staff, especially those interacting with their child on a daily basis like teachers and paraprofessionals, have been kind and supportive for parents facing this scary new trajectory.

> *"It was done in a very supportive way. I didn't feel like there was something wrong in a bad way with my child. They wanted to help."*

- Some school staff, especially teachers, paraprofessionals, and others regularly interacting with children and their families, have been very helpful in navigating the rest of the system, going beyond their explicit roles to help the families they work with.

> *"His teacher is an advocate for him. His general education teachers have been good. His therapists love him and he loves them."*

- Flexible, person-centered approaches from schools worked well for families.

> *"Knowing that each child is different and each child has something to offer, and finding out what that is, really being flexible and being willing to meet kids' needs are probably the two biggest things."*
>
> *"By and large, I feel like the approach to us has been, 'what do we do as a group to make this work?'"*

Areas to improve

Families also discussed negative experiences they had in working with schools.

- This phase was where parents most frequently spoke about having to fight for services and accommodations their child needed to be successful. Parents commonly spoke about having to fight against school administrators and those working for the district; they were generally more positive about their interactions with school staff who work directly with children and their families.
- School officials have been resistant to provide a determination of autism on a child's IEP. Parents who know the importance of having a determination of autism will sometimes have to bring back evidence of their child's diagnosis to essentially force the hand of school officials. Parents must become experts in what the schools are legally obligated to do as they push the school to provide the determination of autism on the child's IEP and follow the plan that is stated in the IEP.

> *"I have learned the IEP inside and out, and I think sometimes they prefer it if you don't know so much."*
>
> *"They kind of try to get away with something and you have to let them know that you know they can't."*

> *"I do feel like the system is designed for me to be the one to go in, asking for what I know they can give, rather than being offered a smorgasbord of options. But there's a limited scope of what's even offered, so that I don't go in asking for the gamut of what I could get for him. I just think it's designed that way… I have to be educated in special education law to really know what I could have."*

- Parents reported that schools will often resist giving the specific identification of "autism" but instead opt for "developmental delay" or other diagnoses. This prevents children from receiving services that will best help them succeed.
- Parents mentioned having to leverage a medical diagnosis of autism to get an educational determination.
- Parents mentioned working to get everything in writing from school staff so that there are actual plans that the school is legally responsible for following.
- Even when parents have positive encounters with school staff, they still reported having to do a lot of education for school staff about autism and how to support their child.
- Parents frequently spoke about how children have to fail academically to get on an IEP. This can be difficult for autistic children and youth without intellectual disability who might otherwise excel in school aside from executive functioning components (like handing in homework) and socialization with peers and teachers.

> *"The school experience can be a nightmare because they're higher functioning and put into a general education setting, but there's not enough knowledge or supports to help those students."*

- Autistic children without intellectual disability are often able to mask their autism for periods of time during the school day. They then "let it out" once they return home, which causes a great deal of stress for parents as they cope with these outbursts and try to explain to professionals the entirety of their child's struggles.
- Different school districts have widely different resources and services they can or will provide. This amplifies existing disparities between families and communities with differing levels of income and wealth; children from lower income communities go to schools with fewer resources, leading to worse experiences and outcomes for children with autism and their families.
- Parents can have radically different experiences with different schools within the same district as their child moves from elementary school to middle and then high school. Some of this was attributed to the teams of professionals working at the different schools, as well as different cultures across the different schools.
- Bullying is a major problem for children on the autism spectrum; schools frequently do not adequately address parental concerns about bullying, according to many parents we spoke with.

STAKEHOLDER FEEDBACK:

We spoke with stakeholders who work in this phase of the journey to gather their insights about what is working well and what could be improved. When the system works well, stakeholders mentioned the following positive aspects:

- Required screening for children entering Kindergarten, which can identify children who need additional services and supports.
- Special education teachers who are trained in autism and how to support children with autism.

Challenges include:

- Difficulty navigating the education system.

  - Feeling overwhelmed upon entering special education services.
  - Stigma around accessing special education.
  - Education and health care are not delivered in a coordinated and comprehensive manner; parents are left to be the coordinator for both needs.

Considerations

We offer the following considerations based on the information outlined above.

- The Minnesota departments of Human Services, Education, and others in the interagency autism team should provide greater guidance and education to school districts about their obligations to make and follow IEPs for children with autism, as well as what services and supports are broadly available for children with autism.
- Some parents mentioned having to leverage a medical diagnosis of autism to get an educational determination. This adds another step for parents trying to access services and supports for their child with autism. Schools should more accurately identify autism in students and be willing to record it as the official educational determination. More research is needed to understand why a school district may resist providing a specific educational determination of autism.
- The Minnesota departments of Human Services, Education, and others in the interagency autism team should consider ways to streamline the medical diagnosis and educational determination processes so that families do not have to go through the two separately.
- School staff across the state should be given consistent training about working with children with autism, including specific training on how to support children with autism, including those who do and do not have intellectual disabilities, and their families. This training could focus on how school staff can work with parents to create an IEP that is flexible and person-centered, as every child with autism has their own unique challenges and strengths.
- As the Minnesota Department of Education, school districts, and others address issues related to bullying, they should consider the specific ways that bullying impacts children with autism and how these challenges can be more effectively addressed in schools.
- The Minnesota Department of Education could work with advocacy organizations and parents to create a packet of information for parents about navigating IEPs and other school-based resources and supports for their children with autism.
- The state legislature and communities around Minnesota should provide greater financial support for teachers, principals, and school districts. Increased funding can allow schools to better train their staff, hire staff with special training in autism and related services, and have resources available to all children and families, including children with autism.

PHASE 6: HEALTH INSURANCE

Key touchpoints

Phase 6
3.3

Families of a child with autism navigate a complex health insurance system with varying success to ensure that services for their child are accessible and affordable for their families. Families often have private insurance, most frequently through an employer; however, private insurance often does not cover all the services families need to access for their child. Families with private insurance may complement their coverage with Medical Assistance (MA); they are not necessarily exclusive and can be used together to cover the cost of services. Families may be eligible for MA because of their income or their child's disability status, as determined by the State Medical Review Team (SMRT; the determination that a child is disabled due to autism and/or another condition is commonly referred to as being "SMRT'ed"). Families that surpass income caps for MA may buy in to the Tax Equity and Fiscal Responsibility Act, or TEFRA, with a monthly parental fee, which is calculated on a sliding scale based on household income. (TEFRA allows states to expand MA to individuals and families above the income threshold; this is not available in all states, but has been adopted by the state of Minnesota.) MNSure is Minnesota's health insurance marketplace that allows families to compare health insurance options and see if they qualify for medical assistance.

During this phase of the journey, insured families will encounter:

- Private insurance, through an employer or the insurance marketplace

and/or

- Medical assistance accessed through programs like MNSure and TEFRA (Tax Equity and Fiscal Responsibility Act expansion of medical assistance to those with incomes above the eligibility cap)

Note: We asked about health insurance and waiver services separately; however, families have a hard time separating waivers from health insurance,since both are a financial means to accessing services. We encourage readers to consider that these experiences become muddled in parents' minds as they review these findings.

Positive experiences

Families discussed their positive experiences with becoming eligible for and using health insurance of varying types.

- Parents who have been able to access MA are incredibly positive about the relief it brings to their lives, from reducing their levels of stress around family finances and expenses to reducing the amount of time they spend researching the costs associated with different services for their child.

> *"There are many, many things that are offered between the waivers, TEFRA, and social security [SSI] that can really help support a family trying to raise a child with autism."*

- Parents with dual insurance are generally positive about their experiences. These families mentioned that MA will pick up whatever costs their private insurance does not cover, and that paperwork is largely handled by professionals without much being asked of the parents themselves.
- Parents' knowledge that services are available and affordable to them once their child is on MA gives them a sense of agency and control over their family's approach to caring for their child. Parents whose child received MA

frequently noted that they can base their decisions about the services they access on their kids' needs, rather than the cost of the services.

Areas to improve

Respondents noted challenges to accessing and using health insurance, as well as changes that could be made in order to improve the experience of families as they navigate health insurance.

- Parents frequently have to learn about their different insurance options often through other parents of children with autism. Parents often "don't know what they don't know" in this phase; they don't know that MA might be available to their child (even if they already have private insurance) or that TEFRA exists for those who earn too much money to qualify for MA. Professionals they encounter throughout the system very rarely mention to parents that they could pursue this type of health insurance.

> *"To be honest, I didn't know about 90% of what's available until other parents told me that there were services they were receiving."*

- For parents with private insurance only, services are often prohibitively expensive and a lot of parental time and energy is spent on figuring out what will or will not be covered by their child's insurance.

> *"It feels like you're begging to get your child the basic help and services they need. It's horrible."*

- The process of getting their child on MA can be very difficult and confusing for parents. Parents frequently do not know that there is a disability route to get on MA (even if household income is higher than the cutoff) and that you can pursue this route with an autism diagnosis.

> *"For behavioral therapy we had to have Medical Assistance for them to be in the program in [name of provider]. As soon as that was done we stopped MA because it was so frustrating. When the tax people tried to get information it was circles, then we would lose our TEFRA payments. [It was] time consuming. I would have to set aside hours to be on hold, [I] missed time from work. "*

- TEFRA fees can be very expensive for families; many families will stop accessing TEFRA and instead pay more out-of-pocket for services for their child. TEFRA fees are based on a sliding scale, so parents with higher incomes pay higher monthly fees. Some parents noted that high-income families can also have high expenses, so income levels are not a perfect indicator of their need for assistance.
- Paperwork can be incredibly challenging for families. Parents are required to keep large amounts of documentation from the variety of professionals and organizations they work with. This requires organization and attention to detail. Parents often noted ways in which they felt fortunate, like having English as a primary language or having high levels of education, when discussing paperwork challenges. They noted that without those privileges, they would not have been able to access certain services for their children.
- Parents spoke about being overwhelmed with other components of taking care of their child, which leads to them forgetting to submit paperwork. This in turn creates large amounts of stress for parents as they fear losing insurance coverage or having gaps in coverage that would result in high out-of-pocket costs.
- Paperwork sometimes falls through cracks at the county, which may include long delays, county staff saying they never got paperwork that parents sent in, county staff not sending appropriate paperwork to the families,

etc. Parents discussed how the county will threaten to drop a family's medical coverage if they do not get paperwork submitted in time, which causes an incredible amount of stress for parents.

> *"It's confusing even as an educated English speaker. Half the time I'm asking on the Facebook special needs support group 'Am I supposed to be filling out this form with my income information? Or is this for my son who has zero income?' Because it's confusing because they send the same form for a toddler as they would send to an adult who maybe has an income."*

> *"The other thing that is very challenging with the Medical Assistance is that they auto-generate a letter saying that your services are going to be cut off 15 days before the end of a month. They send that letter to everyone whether they got your paperwork or not. I've actually called numerous people because I have two children on two different types of Medical Assistance, and they're like, 'Oh, we auto-generate that letter.' Well, that's concerning to a parent who has a child who is in services that needs that coverage."*

- Parents are not able to easily connect with county staff or health insurance company representatives to get questions answered. These parents discussed not being able to get a hold of an actual person to address their questions and being sent in circles by different staff and offices. Parents may be repeatedly re-routed to different staff and offices, and never being able to find someone to answer their questions.
- Some parents noted the difficulty of not being able to use email to ask basic clarifying questions. These parents discussed how they are required to speak over the phone with staff to have questions answered because of potential confidentiality issues. They noted that there should be some FAQ pages or an email account to ask clarifying questions about the paperwork.
- Split families and families with access to different insurance options through their employers encounter another layer of difficulty in using health insurance, as they determine which parent's insurance to use for their child. This results in large amounts of parental time and effort to determine which insurance will provide better coverage for their child's needs.

STAKEHOLDER FEEDBACK:

We spoke with stakeholders who work in this phase of the journey to gather their insights about what is working well and what could be improved. When the system works well, stakeholders mentioned the following positive aspects:

- Effective navigation by a county's financial worker to the State Medical Review Team (SMRT) allows families to access TEFRA. The financial worker identifies that the family has made a claim of disability, sees their financial information, and directs the family to receive a MNChoices assessment, if the family is interested. Then they send the family to the SMRT team. The SMRT team then conducts an interview with the parent or guardian.
- The SMRT hotline is available daily from 7:30-4:30; it allows families with questions about the process to speak directly to their disability analyst.
- Helpful navigation of county services.
- Effective coordination with families, counties, providers, and school systems.
- Language supports for families with limited understanding of the English language; the SMRT team has staff who will compete the disability worksheets over the phone with families in various languages.

Challenges include:

- Barriers to connecting families with county-based services. Large counties are overwhelmed by the volume of cases coming in, and sometimes individuals get lost.
- Inconsistency among counties; each county will make referrals to the SMRT team in different ways. This makes it difficult for the SMRT team to communicate with families about the process and how to navigate through it.
- Staff capacity issues within the SMRT team, which causes a backlog of cases and leads to long turnaround times. Addressing this requires greater financial support as allocated by the legislature.
- A lack of:
  - navigation services for families to understand how to get SMRT'ed, what TEFRA is and how it could be useful for their family, and where to go after getting SMRT'ed or getting access to TEFRA.
  - consistent and reliable internet access for families across Minnesota; high-quality internet access would allow them to learn more about the system and how to access services and supports.

Considerations

Consider the following, based on feedback and experiences of families of children with autism.

- Counties should identify ways for parents to ask clarifying, non-confidential questions in a streamlined and efficient way, like through email.
- The Department of Human Services could provide FAQ sheets that cover common questions about major pieces of paperwork that parents of children with autism must fill out as they access MA and/or TEFRA.
- Parents commonly discussed issues in which counties lose the paperwork they have submitted. This can cause great stress for already overwhelmed families. Counties should explore ways to streamline the paperwork process and increase their staff capacity to process paperwork and ensure accountability to families.
- Families who make too much money to qualify for MA may experience financial hardship as they pay for services and insurance. Those who earn more than the cut-off point for MA do have access to TEFRA, but some parents choose to not access TEFRA because of high parental fees, and parents who do not know about TEFRA are left to only use private insurance. These parents often choose to take on debt to ensure their child receives the care they need.

> *"If we would have met income requirements, I could've gotten all these things paid for and qualified for a lot more. So making too much money actually kind of put us in a bad spot. We just took on the debt at the time."*

> *"Right now, we're having to choose between paying our mortgage and paying our medical bills…That's been probably our biggest struggle with accessing additional resources. And the funny thing is my husband barely makes $45,000 a year. Barely. And we still don't qualify for assistance."*

> *"It's incredibly disappointing to see I have a child who has a medical and educational diagnosis and a need for services beyond what special education can provide, and we are financially unable to pursue those. We don't make a ton of money. My wife works for the school district, I am an athletic trainer, but we were told we make too much money to help our child be healthy and successful."*

PHASE 6.5: CASE MANAGEMENT SERVICES

Key touchpoints

Phase 6.5
3.7

After a child is diagnosed with autism, they may access case management services through the county. Case management aims to help families navigate the system and determine what additional services and supports they may be eligible to access. Families may access these services at a variety of points.

Case management is a voluntary service offered by counties, and families must contact the county to request it. There are a variety of types of case management available to families. Once a family requests case management, they are sometimes referred for a MNChoices assessment, as detailed below, which is used in an intake meeting with a county staff member as they identify the family's needs.

Note: While we sought feedback specific to case management services provided through the county, families struggled to separate case management services they received through the county from case management they received through other organizations, like their school district or hospitals and clinics they work with.

Positive experiences

Families discussed positive experiences they have had in accessing case management services.

- Those who have effective case managers are grateful. A primary struggle for families throughout the entire system is knowing what services are available and how to access them. Receiving assistance from a case manager in navigating the system can be incredibly helpful for parents.
- A primary way that case managers have helped families is that they are aware of and can steer families to waiver services that they might be eligible for. Waivers are a common area in which parents "don't know what they don't know," and having a case manager flag that these services are something worth pursuing can make a significant difference for parents of children with autism.
- Some parents discussed ways that their case manager has served as a co-advocate for their child with autism. Having someone within the system who knows about the needs of the family can be valuable.
- Parents are often overwhelmed by not having one key person they can call when they have questions or do not know where to go next. Case managers, if they are responsive, can alleviate that stress by being that one person families can call and discuss their questions and concerns with.

Areas to improve

Families discussed challenges they have experienced in using case management services, as well as suggested improvements to make to this aspect of care coordination.

- Case managers may not be able to provide complete information about available services and supports. Parents do not think of case managers as being specific to one aspect of county services or tied to specific waivers they receive. They typically believe that case managers should be able to speak to the wide range of services that are available in the county and across the service system. Because of this, they grow frustrated with the case management system and sometimes stop reaching out to their case manager.

- Parents are unsure of what is within the scope of the case manager's job. Parents do not receive clarification about what they should expect from their case manager and what to not expect of their case manager; parents expressed frustration with this lack of clarity.
- Parents continue to think of themselves as their family's case manager. Because parents really do have to serve as the primary care coordinators, researchers, and advocates, parents often do not think of their case manager as someone who reduces their own workload.
- Parents indicated that case managers varied widely in how helpful they are. Parents who were happy with their current case manager often expressed fear that they would lose that case manager.
- Staff turnover is a major challenge that families encounter.

> *"I sent an email, I didn't know this woman [case manager] quit, and I was waiting to hear back, and I had to call a supervisor and no one got back to me. It took me three months before I realized no one was working on my case. That's why there are so many parents on blogs helping each other, because no one else is helping."*

- Parents spoke about challenges working with case managers who have been contracted by the county to provide this service. These case managers typically provided worse service, according to parents. Parents noted that they understand that provider shortages force counties to contract out work, but express frustration nonetheless.
- Case managers often have limited time available to answer parents' questions. Because case managers typically work during business hours, parents who work full time or close to full time struggle to find times to contact their case manager.

STAKEHOLDER FEEDBACK

We spoke with stakeholders who work in this phase of the journey to gather their insights about what is working well and what could be improved. When the system works well, stakeholders mentioned the following positive aspects:

- Strong relationships with other phases of the system, including school districts and medical professionals.
- Consistent check-ins with families.
- Successful connection of families with services and supports by case managers.
- Collaboration with other types of county professionals and service systems; case managers have colleagues to turn to when they do not have the answer.

Challenges include:

- Staff shortages, particularly among personal care assistants (PCAs) and waivered service providers. This makes it difficult for case managers to connect families with services they are eligible for.
- Staff shortages among case managers themselves; this leads to caseloads that are too large.
- Case managers must know an incredible amount about the system; it is difficult to adequately train case managers to become experts on a very complex system.
- It can take time for case managers to fully understand the challenges a family is experiencing and what services would be the right fit for the family.
- The system is not perfectly suited for children with autism. There are a variety of waiver services that case managers may be able to connect families with, but autism awareness and increased prevalence rates occurred after the system was set up, so the waiver and service options do not always neatly align with a family's needs.

Considerations

Below are a few considerations, informed by families' experiences with case management.

- As with other areas, find ways for families to state their needs and have those familiar with the system try to find resources and tools for families. Families feel they need to come to their case manager with the "right" words to get access to services.
- Provide training to case managers about the range of services and supports available to families who have a child with autism, and train case managers to proactively offer this information to families who may benefit from these services, even when families have not specifically asked for them.
- It is likely challenging for case managers to know the right things to recommend to a family of a child with autism, due in part to the vastly different ways autism shows up in children. The Department of Human Services could provide training to case managers with this in mind, or even create positions for autism-specific system navigators with this specialized knowledge.
- Increase training for other staff so that there is consistent information coming both to and from case managers.
- Parents noted difficulty in reaching their case managers by phone. They understand that case managers are often overloaded with work, which they believe to be the cause of these dropped communications. In addition to exploring ways to increase case management capacity, counties should consider ways for parents to more easily get questions answered and contact their case manager, including outside of regular business hours available.
- Counties should work on strategies to limit case manager shortages and reduce turnover within the field.
- The Department of Human Services should work with the state legislature and other agencies to address the shortage of case managers.

PHASE 7: EARLY INTERVENTION SERVICES

Key touchpoints

Phase 7
4.1

Early intervention services, specifically Early Intensive Developmental and Behavioral Intervention (EIDBI) and Children's Therapeutic Services and Supports (CTSS) are benefits available to children and youth age 0-21 in Minnesota who are on the autism spectrum. They provide a set of therapy and mental health services that aim to improve the quality of life for children with autism and their families. EIDBI and CTSS services can only be provided by agencies who have been appropriately certified by the Minnesota Department of Human Services. The Minnesota Health Care Programs Provider Directory includes a statewide list of providers. Children must have had a diagnostic assessment (DA) to access CTSS services and a comprehensive multi-disciplinary evaluation (CMDE) to access EIDBI services; a CMDE can meet the requirements of a DA in granting access to CTSS services. Families with Medical Assistance, Minnesota Care, or TEFRA can access EIDBI services. Some private insurances cover the service as well. County officials can help families get connected to early intervention services. These services are available for children who have completed a DA or CMDE, regardless of whether or not the family has gone through the MNChoices assessment because they are funded through health insurance. Children may receive a blend of EIDBI and CTSS depending on their unique needs.

Early Intensive Developmental and Behavioral Intervention (EIDBI) includes:

- Individual and group therapeutic intervention (such as ABA or DIRFloortime)
- Family/caregiver training and counseling

Children's Therapeutic Services and Supports (CTSS) includes:

- Psychotherapy
- Skills training
- Day treatment
- Crisis services
- Case management services

For more information about EIDBE and CTSS, please visit the Department of Human Services' Comparison of Children's Therapeutic Services and Supports (CTSS) and EIDBI.

Positive experiences

Parents noted some positive experiences they had when receiving EIDBI or CTSS services.

- Parents who access therapy for their children through EIDBI or CTSS speak positively about the outcomes for their child. Seeing their child progress can give parents a sense of hope for their child's future.

> *"A year ago, he wasn't talking. And now he's saying 3- and 4-word sentences. He was throwing temper tantrums all the time before, and now he's doing a pretty typical amount. He wasn't mimicking anything at all, but now he's doing it… How far he's come in the past year is pretty insane."*

- Some parents have learned the importance of accessing services at a young age to allow for the best outcomes for their child. Parents discussed how important it is that these benefits focus on accessing intensive interventions at a young age.

- Parents discussed positive experiences working with autism center therapists. They discussed how these therapists are able to forge genuine connections with their child and appear to enjoy the work they do.
- Parents said therapists at these autism centers are often available for questions even once a family has left the center. This is a huge relief for parents who are otherwise overwhelmed and do not know where to go for answers.

Areas to improve

Parents also identified areas where improvement was needed in this phase of their journey.

- Parents struggle to get their child in to an autism center to receive therapy through EIDBI or CTSS. Provider shortages result in long delays to get therapy as families sit on wait lists. This can be incredibly stressful for parents who understand the importance of receiving therapy as soon as possible for their child with autism.
- Some parents discussed concerns with Applied Behavior Analysis (ABA) therapy, which is the most common therapy approach used by EIDBI and CTSS providers. Some concerns are foundational disagreements with the therapy, including concerns about "fixing" children with autism rather than celebrating their differences. Other concerns are more minor, like the use of candy to reward positive behavior.

Considerations

We offer the following considerations based on the information outlined above.

- Some parents were not sure whether or not they accessed therapy through EIDBI or CTSS services. The Department of Human Services could explore ways to help parents understand the benefit and what it means to access EIDBI or CTSS services.
- Some parents noted the helpfulness of autism center websites and that parents of children with autism who do not access EIDBI or CTSS therapy could still benefit from looking at these websites.
- The Department of Human Services should continue efforts to recruit therapists and direct support providers for EIDBI and CTSS certification. The Department of Human Services, in collaboration with providers, should continue efforts to recruit and retain staff at all levels who can provide interventions services for children with autism. The Department of Human Services can also work with colleges and universities to create more programs that train and educate people to go into this field.
- Some parents struggled with the intensity of care, as it has major implications on what their family is able to do outside of therapy. The Department of Human Services, providers, and other stakeholders could consider ways to support these families as they cope with the intensity of these therapeutic supports. This could include ensuring more access to direct support staff who can assist parents in implementing the interventions for their child in their home and in community settings.
- The Department of Human Services and ABA therapy providers could work together to create a document summarizing what to expect from ABA therapy and ways in which parents can influence the therapy (for example, by asking providers to use incentives other than candy and sweets). This document could distill information about ABA therapy to be easily understandable and counteract misinformation about the therapy, as well as give parents a greater sense of agency over their child's therapy.

- The Department of Human Services and other partners should consider ways to communicate with parents about ABA therapy and address any concerns parents have with the philosophy behind it. According to the research literature, ABA therapy modalities are some of the only proven methods to address some of the common problem behaviors and communication challenges associated with autism. There is a vast range of information and misinformation available to parents about ABA. The Department of Human Services and providers should help parents weed through the noise to assess, based on scientific research, which therapeutic options and other interventions are right for their child and family.

PHASE 8: CONTINUED SUPPORTS ACCESSED THROUGH A HOSPITAL OR CLINIC

Key touchpoints

Phase 8
4.1

There are a wide variety of medical and therapeutic services and supports that children with autism and their families can access through a hospital or clinic. These are available for all children with a medical diagnosis of autism, regardless of insurance type or whether or not the family has gone through the MNChoices assessment. However, costs associated with these services may be prohibitive for families in cases where private insurance will not cover certain services. While technically available to all families, these services are not truly accessible for many who cannot bear that financial burden.

Key touchpoints at this phase in a family's journey include:

- Well-child check-ups
- Occupational therapy
- Physical therapy
- Speech and language pathology
- Medications
- Mental health services
- Services for co-occurring conditions
- Referrals for additional service

Positive experiences

Parents discussed positive experiences they have had in accessing services through hospitals and clinics.

- Therapies can improve the child's and family's quality of life. Children are better able to cope with the symptoms of their autism with help from medical professionals and therapists.
- Parents often discussed working with a "superstar" professional who serves as a co-advocate for their child. This often included therapists who work in occupational therapy, speech and language pathology, and physical therapy. These professionals created strong relationships with the children they serve and their parents, and were able to provide families with information and resources even beyond the explicit scope of their role. They were able to help parents navigate the system and access more services and supports to improve their child's outcomes.

Areas to improve

Families identified areas where improvement was needed in this phase of their journey.

- Provider shortages are challenging for families. This makes it so that parents have to face delays to get in to see a professional, and for families in greater Minnesota, they often have to travel long distances.

> *"In the Twin Cities, there are a lot more options and resources. Up here [in the Iron Range in rural northeast Minnesota], none of that exists, and you're scrambling for every piece of it."*

- Parents have to navigate the challenges of their child's autism when seeing providers, especially new providers. Changing routines, navigating new buildings, and meeting new providers can all be challenging experiences for youth with autism.
- Parents often spoke about challenges in finding a provider who is the "right fit" for their child. This is particularly challenging in communities that face provider shortages, in which families have fewer options. Parents also discussed challenges finding a therapist who is the "right fit" for teenagers with autism; these teenagers are still within the service range for pediatric care, though most pediatric therapists are used to working with younger children.
- Parents find the ages at which children can shield their parents from seeing their health records arbitrary and concerning. Some parents reported being surprised to learn that their child may keep certain medical information private from their parents even before reaching age 18. Kids with autism might be having a bad day and choose to have their parents not be able to see their health records or otherwise communicate with doctors/providers, but their intellectual or emotional age is much less than their physical age. Parents are concerned that their child's actions will keep them from getting appropriate care.
- It often takes awhile to see the benefits of therapy. This can be discouraging for parents who feel as though they are swimming upstream against the system and their child's resistance to therapy and other care. Some parents become so frustrated by the distance to providers, wait lists, and other difficulties in getting care that they will drop off of receiving these services.
- Some youth with autism will refuse services, especially those who are in their teen or young adult years. This can add another layer of stress and challenge for parents of children with autism.

Considerations

We offer the following considerations based on the information outlined above.

- Work with parents to ensure they are able to provide consistent care and advocacy for their child with regard to accessing their medical records and communicating with their child's providers about their care.
- Create more built-in incentives or motivators for continuing with a particular service or program, such as motivational stories from other families who have seen good outcomes from the same service or giving them "congratulations" notes for completing certain milestones in therapy.
- Develop resources that are directed to youth with autism to encourage them to participate in the services, including incentives.
- The Minnesota departments of Health and Human Services should work with the state legislature and other agencies to address the shortage of health care providers across the state, with a particular focus on reducing the shortage of providers in greater Minnesota.

PHASE 9-10: MNCHOICES ASSESSMENT, WAIVERS, AND OTHER SUPPORTS

Key touchpoints

Phase 9-10
3.8

Children with autism and their families may have access to a wide range of services and supports provided to them through the Department of Human Services. The MNChoices assessment is a person-centered assessment that aims to holistically understand the needs of anyone who might need services and supports; in this case, the child with autism and their family. MNChoices assessors are trained to know about the wide range of services and supports available to a family and can serve as a first touch with the Department of Human Services, in which the assessor uses the results of the assessment to discuss what services and supports the state can provide to the family.

Waiver services are one component of this array of services and supports provided through the Department of Human Services and counties across Minnesota. The Centers for Medicare and Medicaid Services provide support to states to implement waivers; these waivers provide funding for families to access goods, equipment, and services from professionals to allow them to live at home, rather than an institutional setting. Parents and caregivers work with the county to create plans on how to use the waiver to meet the needs of families. A variety of other services are available to families, including transportation assistance, employment assistance, and parent pay, with which a parent is compensated for their time and efforts to help their child with activities of daily living that would otherwise be done by a personal care assistant.

The MNChoices assessment is an annual assessment to determine eligibility for waivers and other services. These include:

- Home and community-based services waivers, (AC, EW, CADI, etc.) including consumer-directed community supports
- Personal care assistants (PCA) and consumer support grants
- Family support grants, including financial assistance for services and goods
- Supports around housing, essential supplies, transportation, case management, equipment, and employment

Positive experiences

Parents discussed positive experiences they have had in this phase of the journey.

Parents noted positive experiences they had when going through MNChoices assessments.

- This was one of the most positive experiences on families’ journeys. Parents frequently spoke about the helpfulness of MNChoices assessors and the incredible opportunities that are opened by accessing waivers and other services.

- The MNChoices assessment can be a relatively painless experience for families. Parents discussed the convenience of the assessment taking place in their home. They also appreciate that all of the questions seem relevant and offer a holistic view of the child's and family's needs.

  > *"The questions are not always easy to answer… So since someone was there, I could tell her how I was thinking about the question, and she completed it. It's much better having someone come out and do that with you."*

- Parents frequently spoke about receiving information and resources from their MNChoices assessor; this assessor could speak to the wide variety of supports available after a family has gone through the assessment.

Parents who have access to waivers comment on the quality of life change they provide.

- Parents who have access to waivers feel very positive about the opportunities they present for their child. Waivers can provide a set of resources to give families what they need in a flexible way. Waivers can cover medical items that are necessary for the child to have a reasonable quality of life, like a feeding chair for a child with autism who has severe feeding and nutritional issues. Waivers also cover non-medical items that are critical for the child's safety and well-being, like a fence for a child who wanders or compression clothes for a child with sensory issues.
- Waivers, parent pay, and other supports can also allow parents to stay home with their children rather than have to go to work and leave the child with a child care provider which may not be able to handle the child's needs. This is oftentimes a best-case scenario for a difficult situation for parents.

  > *"The parent pay…provides me support for everything I'm doing for her, financially. It takes the burden off me because I do need to be home to make sure everybody's safe around her."*

Areas to improve

Families identified areas where improvement was needed in this phase of their journey.

Accessing waivers and other needed services can be a challenge.

- Parents commonly discussed how they must have the "right" words in order to access waivers and other needed services. Rather than discussing their needs and having waivers suggested to them by county staff, parents often have to learn about specific waiver programs through other means, often other parents of children with autism or other disabilities, and specifically request them.

  > *"If you say 'I'm tired and overwhelmed' you don't get help, but if you say 'I need respite [a specific service that is available through some waivers],' then you do."*

- Parents reported that county staff will even discourage parents from getting access to waivers and other services and supports that they are eligible for and can help their child.

  > *"I called the county to talk about a waiver and the woman said 'what do you need that for? I don't think you need that' after asking me two questions. So I never pursued it… I couldn't work that whole time so we were suffering financially, and we could have actually had help."*

Parents discussed areas where they need more support.

- County staff, including case managers, appear to be overwhelmed with their workloads, according to parents. Because of that, it is hard for parents to get a hold of county staff to get concrete answers to their questions about waiver services.
- Parents reported needing more guidance on how they can and cannot use waiver funds. Parents reported frustration in having their requests denied without clarification as to why. Because they do not receive clarity on what they can and cannot use their funds for, parents often reported feeling as if they are guessing each year.

Paperwork is challenging for parents.

- Parents face many challenges completing the paperwork that is required to access waivers and other needed services. The amount of paperwork and its complexity can be overwhelming for parents. Additionally, many parents detailed experiences they had in which the county lost paperwork they had submitted. It was in this phase of the journey that paperwork difficulties were most frequently discussed; this serves as a barrier to accessing services that can be life-changing for families.

> *"It's hard for people to know who to contact, what to expect, how to answer the questions on the assessment, what their rights are… It's confusing even as an educated English speaker."*

- Parents frequently spoke about having to prove year after year that their child's need for services has not changed. This is frustrating for families who have a child with a life-long diagnosis.

Parents described frustration with some services and supports they have accessed.

- Parents expressed frustration on low caps on their parent pay. They often discussed sensing a preference from the county for parents to use their waiver funds for equipment and professional assistance, rather than receiving parent pay for the work they do. This can add a layer of difficulty for parents, as they noted they spend large amounts of time coordinating with professionals and training them to care for their child. This adds work to their schedule, but it is the only way they feel they can fully access their waivers and other services. Parents expressed frustration at this inefficiency.

> *"I have to locate them. I have to train them. And I have to schedule them. By the time I've done all that, I've spent more time coordinating other people than I would have if I just did it myself. Yet I cannot get any more parent pay. They will not provide more parent pay than the three and a half hours a week that I currently am allotted."*

- Parents frequently discussed challenges with transportation services provided to them in this phase of their journey. Drivers can be inconsistent and noncommunicative, and accessing transportation assistance can be too expensive for families.

> *"Actually, the fact that we have them [transportation services] is amazing, but they're not the best communicators. They don't always get them there on time."*

Some parents experience stress related to their MNChoices assessment.

- Parents discussed stresses they experience in completing the MNChoices assessment. They feel a tension as they need to discuss how their child and family are struggling so that they are able to access services they need, but also do not want to come across as a bad parent or indicate that their child is "failing."

STAKEHOLDER FEEDBACK:

We spoke with stakeholders who work in this phase of the journey to gather their insights about what is working well and what could be improved. When the system works well, stakeholders mentioned the following positive aspects:

- Families are connected to financial supports that improve their quality of life.
- MNChoices assessments appropriately identify areas in which the county can support families of children with autism.

Challenges include:

- Shortages of MNChoices assessors.
- Families are unclear about what point in the process they should get a MNChoices assessment. Some counties tell families to get a MNChoices assessments before they get SMRT'ed, others say they have to get SMRT'ed before they can have a MNChoices assessment. A MNChoices assessment is available at anytime, though parents are often not aware of this.
- Families are unclear how to move forward in the process. Often, parents are told to "call the county," which does not provide much clarity for families. They should be given information of what phone number to call and how to get to speak with a person.
- Minnesota has a county-based system, which is different than some other states. This creates a more disjointed system of care in which families experience different processes and opportunities based on what county they live in.
- Children with autism who have a high IQ fall into a "gray area" in which many services don't align well; their needs are not severe enough to qualify them for some supports through waiver programs.

Considerations

We offer the following considerations based on the information provided to us by parents.

Considerations for the MNChoices assessment

- Parents sometimes discussed how the MNChoices assessment itself is demoralizing, as parents must go through a list of the things their child cannot do. The Department of Human Services could consider ways to alter the MNChoices assessment to include more strengths-based questions, or provide materials for families who have gone through the MNChoices assessment that are hopeful and encouraging.
- The Department of Human Services should consider ways of minimizing the annual re-assessment process for people who have medical conditions or disabilities that result in their needs being unlikely to change from year to year.
- The Department of Human Services could work to increase parental awareness of how the Diability Hub and staff at the Department of Human Services can help families who feel they are receiving conflicting messaging from county staff or are otherwise confused by the system.

Considerations for waivers and other services and supports

- The Department of Human Services should consider ways to increase general knowledge about what waiver services are and how families can access them. This phase was an area in which many parents spoke about how you “don’t know what you don’t know.” Many parents who would be eligible for waiver services and could benefit from them simply do not know that they exist.
- The Department of Human Services could explore ways to provide more clear guidance to families (and counties) about how they can and cannot use their waiver funds. This would streamline the process for families and county staff who review proposed budgets.
- The Department of Human Services and counties could streamline paperwork processes and make paperwork easier for families to complete. This could include FAQ sheets about common forms, an email address where parents could send in non-confidential questions, and greater staff capacity at the county to answer questions from parents.

PHASE 11: COMMUNITY SUPPORTS AND SERVICES AVAILABLE THROUGHOUT THE LIFE SPAN

Key touchpoints

Phase 11
3.7

There are a variety of community-based services available for children age 14+ who are preparing to transition into adulthood. These include programs that teach independent living skills, provide assistance to access postsecondary education, and equip young adults with workplace skills.

Relatively few of our respondents had accessed these services. This is partially due to the age of our respondents' children: 26% of respondents had a child age 14 or older.

Community services and supports available throughout the life span (age 14+) include

- Waiver services, like case management, employment assistance, transportation services, and access to equipment and supplies
- Personal Care Assistant (PCA) services
- Employment services
- Home care nursing
- Home health aides
- Independent living assistance
- Postsecondary education assistance

Positive experiences

Parents discussed positive experiences they have had in this phase of the journey.

- Most parents who had encountered this phase solely spoke about experiences with a personal care assistant (PCA). These PCAs provided helpful caregiving support for families, which relieved some parental stress and gave parents opportunities to see to other responsibilities. When parents found a PCA who was a good fit for their family, they would create a genuine bond as a family with their PCA. There were several instances in which a PCA stayed with a family for years.
- Parents who did access this aspect of care spoke about the helpfulness of the services their child received. These services can instill hope in parents that their child can live a meaningful life that is more independent than parents initially assumed was possible.

> *"They just open up so many opportunities for [my son], especially transitioning into the adult workforce and independence, there's just so much offered and so much available for him to access."*

Areas to improve

Families identified areas where improvement was needed in this phase of their journey.

- This is a key area in which parents "don't know what they don't know." The thought of their child transitioning to adulthood (and increased independence) can be a stressful period of time for parents; knowledge of these services could really help parents feel hopeful.

> *"I don't know what to even be asking for. I don't know what to be searching out."*

- Throughout the service system, parents learned of available opportunities from other parents who had already been through the system. Parents of young adults have fewer "veteran" parents who have been through the process who they can look to for advice.
- Provider shortages were mentioned during this phase as parents spoke about challenges getting PCAs for their teenager or young adult. PCAs are often young adults, and there is high turnover in the field according to parents, so they struggle to find a qualified professional who will stay with their family for a long stretch of time. This turnover among PCAs can be especially challenging for teenagers and young adults with autism, who crave routine and consistency among those they interact with. Some parents discussed paying their PCA extra to incentivize them to stay in the profession and with their family.

> *"Staff turnover… kids on the autism spectrum have a really hard time with change… they don't deal with change very well, then every month or every other month, you have staff changing. That's really hard on them."*

STAKEHOLDER FEEDBACK:

We spoke with stakeholders who work in this phase of the journey to gather their insights about what is working well and what could be improved.

Challenging aspects of the system include:

- Parents are often getting connected to information about transition services when their child is around 17, rather than 14; parents need more information sooner.
- Parents often have to reach out to get connected to these transition services, rather than professionals in the system connecting parents to them.

Considerations

We offer the following considerations based on the information provided to us by parents.

- The Department of Human Services and other State Agencies such as the Department of Employment and Economic Development (DEED), and the Minnesota Department of Education (MDE) could provide more information to parents about what transition services are available, and make this information available earlier so that parents have time to plan. This can allow for a smoother transition into adulthood.
- The Department of Human Services and their partners should work together to raise awareness among parents of children with autism that they should start thinking about their child's future and adulthood from the time they are young, including exploring interests and potential jobs to help their child gain skills that will help them in those positions.
- The Department of Human Services could increase training for providers who interact with teens on the autism spectrum to ensure they are aware of the types of transition supports that are available and know how to communicate with parents about these opportunities.
- The Department of Human Services and other stakeholders could consider ways to recruit and retain more PCAs to reduce provider shortages.

PHASE 12-13: OTHER ORGANIZATIONS AND RESOURCES

Key touchpoints

Phase 12-13
4.4

Families can access organizations, networks, and other types of community-based resources throughout the entirety of their journey through the system. These include formal advocacy organizations like The Arc, the Autism Society of Minnesota, Family Voices, and PACER, as well as informal networks, like those on social media. These organizations and resources provide an avenue for parents of children with autism to learn about autism, services and supports that might be useful for their family, and what benefits might be available to them. They also serve as a way for parents to meet and support one another.

Positive experiences

Parents discussed positive experiences they have had in this phase of the journey.

- Parents spoke positively about their experiences with advocacy organizations and professionals within this sphere. They received support, access to information to resources, and connections with other parents going through similar experiences.
- In particular, parents highlighted positive experiences working with PACER. PACER staff provided a wealth of information for parents as they learned how to interact with the school system to ensure their child accessed the supports they needed. PACER staff would often come to IEP meetings with parents to support them, and many parents spoke about PACER staff as being co-advocates for their child.
- The Autism Society of Minnesota and The Arc were highlighted as being particularly helpful in providing credible and useful information for parents. Many parents went to conferences or informational sessions offered by these organizations that helped them learn to be advocates for their children to ensure they got the services and support they needed.
- Facebook groups are incredibly useful for parents. Oftentimes, Facebook groups are a primary source of information for parents. This is often how they find the "right" words to request services. Parents commonly spoke about how they "don't know what they don't know," so hearing about other parents' experiences exposes them to new opportunities to pursue.
- Social media groups also serve as common spaces for parents to feel that others understand what they are going through.

Areas to improve

Families identified areas where improvement was needed in this phase of their journey.

- Parents frequently spoke about having a hard time making time in their schedules or getting to informational sessions facilitated by advocacy organizations.
- Some parents were not aware of many of the advocacy organizations we listed for them. It seems that parents need to get connected to just one organization or network to get connected to more; the organizations and

informal networks were able to share information about what is available. Because of this, some families were extremely well-connected to the wide array of advocacy organizations available, while others had no experience or very limited experience with them.

- Facebook groups can spread misinformation that's potentially harmful for kids with autism and their families, especially around "cures" for autism that are not evidence based or even harmful.

STAKEHOLDER FEEDBACK:

We spoke with stakeholders who work in this phase of the journey to gather their insights about what is working well and what could be improved. When the system works well, stakeholders mentioned the following positive aspects:

- Information and resources about families' rights, what is available to them, and how to access services.
- Co-advocacy with parents.
- Advocacy training for parents.
- Guidance on what to expect as they move through the system.
- Consistent check-ups on families to see whether or not they have been successful in the efforts the advocacy organization guided them to do.

Challenges include:

- A disconnect between how services and supports are explained and how families experience them. This adds to navigation difficulty.
- Different jargon used by different fields and organizations; for example, the medical and educational communities use different terminology.
- Fear from undocumented parents of children with autism to ask for or demand more services for their child. These parents are afraid to push back on the system for fear of being deported.
- Language and cultural barriers make service access difficult for parents.
- Fear of the autism diagnosis for a child, especially in relation to societal stigma around autism, can make parents live in denial of their child's diagnosis.
- Families may be unaware of free resources that are available to them based on their child's disability, rather assuming they are not eligible for these types of support because of their household income. For example, school districts have lawyers available should legal cases come up around IEPs and services for children with autism; families may not be able to afford a private attorney and not know they can access legal representation through the Minnesota Disability Law Center.
- Understanding concrete next steps for families to pursue; often, advocacy organizations must translate the information given to families by other professionals into understandable terminology and concrete next steps.

Considerations

We offer the following considerations based on the information provided to us by parents.

- Stakeholders could consider ways to dispel myths about "cures" for autism, misinformation about ABA therapy, and anti-vaccination information.

  > *"I would say the onslaught of incorrect information and unproven therapies that are thrown at families… We all rely on Facebook and things like that so much to get information, and the majority is incorrect, unproven, and in some cases, harmful. And wading through that, and trying to figure out what is real, what does he really need, what will really help him, or what would harm him. Supplements, chiropractors, specialty diets, listening therapy, all of these things. There's nowhere to go that says "this is real, this isn't." So you're just lost and trying to use your best judgment… You're desperate, so you're willing to try anything."*

- Advocacy organizations should consider ways to expand their reach to better serve parents who do not speak English, are undocumented, have less education, live in greater Minnesota, are introverted, or have autism themselves. These types of parents appear to be less connected to advocacy organizations; these organizations may need to find new ways to do outreach and alter programming to better serve these families.
- Many parents noted a desire for more in-person support groups; support groups offer a powerful way for families to share information and resources and to have someone to empathize with. Some parents suggested there be support groups that are differentiated by severity of the child's autism, which would allow parents with more similar experiences to gather. Teleconference options could be considered for parents who live in more rural areas or otherwise find it challenging to attend in-person support groups.
- Consider a mentorship program for families of children with autism. Adults with autism or parents of an older child with autism could be trained to serve as mentors for families newly navigating the system, providing them with information about what to expect and a role model to help them feel hopeful about their future.
- Facebook groups can be overwhelming to parents; these parents spoke about how other parents seem to look for an outlet for their grief and frustration. This can be too much for other parents experiencing their own stressors and grief.
- Parents spoke about running into experiences in which other parents used Facebook groups to prove that their child and family is worse off than others. Parents noted how toxic this feels, and how it turns them away from joining groups that might provide resources and information to them.

OVERARCHING THEMES

Throughout our interviews with parents, we heard some themes emerge across phases. These were oftentimes consistent hurdles and barriers that stretch across the entire system of supports for families with a child with autism. These key themes are summarized below.

Barriers across the service spectrum

“You don’t know what you don’t know.”

In general, parents expressed frustration at the lack of available, easy-to-understand information about what the spectrum of services and supports are for children with autism in Minnesota. Parents often learn about what is available in a piecemeal fashion from their families, friends, and informal networks, such as Facebook groups.

> *“I do believe there is a whole host of things that I have not known about that I should have available to him, but what I don’t know, I don’t know.”*

Figuring out next steps is incredibly difficult for parents; additional navigation support is needed.

Parents struggled to know how to learn about and access needed services and supports for their child. In some cases, professionals provided suggestions for concrete next steps, but many times, families were left to figure this out for themselves. This was especially challenging for families who moved to Minnesota and who had previously had to navigate a completely different system in another state, and was also a pervasive challenge for families who have been Minnesota for their entire experience of having a child with autism. Parents frequently provided feedback across the entire system that additional navigation assistance would reduce their stress levels and ensure their child has access to the services and supports they need and are eligible to receive.

> *“I did move from one state to another state. I didn’t know how to navigate services here in Minnesota. And I didn’t really have anybody that I knew to go to, to help me navigate the services or programs. You hear names of organizations and groups thrown out there, but nobody said ‘you have to call this one.’”*

> *“I don’t know, what can you do? Help me. Give me some ideas. Give me some options. Give me someplace to start. Otherwise, I’m doing it all on my own.”*

Parents need to learn to use the “right” words to gain access to services and benefits.

Parents frequently expressed frustration that they must specifically ask for services and benefits that they are eligible for. Many noted that before working through the system, they assumed that county staff and staff at the Department of Human Services, service providers, and others working within the system would be able to tell them about benefits and services that might be available to them. Instead, common understanding among parents of children with autism is that staff will not offer these services or grant access to them without a parent explicitly knowing the name of a benefit or waiver and asking for it.

However, most parents do not know the intricacies of what benefits they should be asking for. A key barrier to parents being able to get the services and supports their child needs is the lack of information sharing from those knowledgeable of the system. Parents noted that they commonly learned about services and supports that are available to them through informal connections, like Facebook groups of other parents of children on the autism spectrum, family members who have gone through the system with their own children, or other word-of-mouth information sharing. Some likened this to learning the "secret password." Some parents noted how difficult this must be for other parents who do not speak English as their primary language.

Parents also discussed needing to speak to the "right" person and ask the "right" questions. Parents often felt that it was luck that got them the services and supports they were ultimately able to access for their child.

The stress of fighting for access to services and support takes a substantial toll on families.

Parents frequently described what they did for their family as "fighting," and several parents likened going through the system to going to war. Numerous parents discussed the toll it took on their own mental health, the well-being of their family, and their marriages. Many parents mentioned how the effort it took to fight for their child or children with autism was a contributing factor to their divorce. Parents with other children often spoke about how their child's autism and the process of getting them services and supports has taken a toll on their ability to parent their other children, and how their other children have gone through their own grieving and coping processes. While the child's autism itself is no small factor in the reduced quality of life for these families, having to fight through the system greatly compounds this stress.

"Survival mode" can make barriers insurmountable.

Parents of children on the autism spectrum face a wide variety of challenges in everyday living. Because autism is such a broad spectrum, these challenges are unique for every family. They can include protecting their child, themselves, and others from the child's violent or self-injurious behaviors, navigating difficult sleeping and eating behaviors, communicating with a non-verbal child, and negotiating the stigma of autism in social situations, among a wide variety of other challenges. These parents are learning as they go, and often have too few resources and supports to get respite from their caregiving responsibilities or to ensure their own well-being. Because of this, many parents spoke about living in a sort of "survival mode" in which they were taking life one day at a time. While living in this survival mode, challenges and barriers that might otherwise be manageable become insurmountable. Confusing or excess paperwork, poor communication from providers, county staff, or medical professionals, and significant wait times and delays in getting services and supports can force parents to a breaking point, causing them to give up on accessing these services and supports.

Provider shortages are a barrier to service access.

Parents of children on the autism spectrum and professionals working within the system highlighted the impact of provider shortages across the system of services and supports. Because of these provider shortages, families must wait for long periods to get a diagnosis or access service and, in some cases, must drive long distances and incur travel expenses to access care for their child. This provider shortage is challenging for professionals working within the system as well, as they experience large caseloads and are overwhelmed by the amount of work each staff member is expected to do.

Disproportionate caregiving and emotional burden falls on women.

Caregiving for a child with autism is demanding in time, resources, patience, and parenting skills. Many parents we spoke with during this study mentioned reducing their hours at work or leaving the labor market entirely to care for their child. In nearly all of these cases, it was the mother of the child who reduced their hours or left the labor force. Additionally, female respondents frequently spoke about difficulties in getting their male partners "on board" to either accept their child's diagnosis of autism or assist in their child's caregiving, including taking them to therapy appointments, meeting with school staff, and other touchpoints with professionals in the system.

Mothers were disproportionately likely to spend their own personal time researching autism and connecting with informal networks of other parents, such as social media groups of parents with autism. Mothers were also more likely to spend time figuring out their family's health insurance and related benefits. Some mothers referred to navigating the system as their "second job." For example, one respondent worked with their employer to work four 10-hour days, allowing her to then dedicate a full workday each week to scheduling appointments, managing phone calls with the county, and seeing to other logistical work around their child's autism.

In each phase of the system, we asked respondents who helped them the most during that phase. We spoke about this broadly, noting that it could be professionals, family, friends, or anyone else. The most common answer we received throughout the system was that mothers did not receive much help. We frequently heard responses of "it was all me," or "no one helped me." This disproportionate level of attention and time spent on caregiving for their child is reflected in our respondents' demographics; as noted above, 95% of our respondents (who opted in based on recruitment of "parents of children with autism" from Wilder and the Department of Human Services) were female.

> *"It's more than just coming home and doing all the dishes, and doing all the laundry, and doing all the cooking and everything else. When you add in also taking care of a child with special needs, that's not just a double day, that's a triple. And we don't have that conversation as a nation." –Female respondent*

> *"I think that men don't like sharing their feelings. But it's weird though… You talk to some different autism moms, and the husbands don't even like to say that their son has autism. They like to just not talk about it and pretend it doesn't exist. It's like, it's not the end of the world. They're still your son, move on." –Male respondent*

Professional experience in the system is beneficial for parents.

The system of services and supports for children with autism is complex and difficult to navigate. Many parents we spoke with had professional experience in some aspect of the system, including education (including special education), health care, and working for the county. This professional experience gave these parents knowledge of how to navigate the system, which allowed for greater utilization of services and supports and a better overall experience in doing so. Working within the system also expanded networks for parents of children with autism.

> *"Insurance? Nobody [helped me] really. I did that myself with researching on the internet and asking questions. We didn't have a lot of choice because you go with whoever your employer has. I was a social worker at the county, so I had access to information that maybe the general public doesn't as far as manuals for the financial workers and things… Although even inside it's pretty difficult to navigate."*

> *"I look at the families that I work with that are homeless and there's usually other barriers there, including mental health and everything else. And then I always just think that it's got to be 10 times harder when you don't understand the system because the system is really complicated, even for those of us that work in it."*

Parents' networks play a substantial role in their ability to access services and supports.

We see throughout this study that formal and informal networks that parents have made a huge difference in their ability to access care and financial supports for their family, and to do so in a way that is less frustrating than for those without access to networks with information and connections. Parents turn to those they know who have been through a similar situation or who have professional expertise in the area for guidance, information, and resources.

Schedules are a consistent barrier to accessing services and supports.

Oftentimes, doctors, therapists, county staff, and other professionals working within this system of supports work a standard 9 am-5 pm day. This is incredibly challenging for families of children with autism as they seek to juggle careers, caregiving responsibilities, and care coordination. Parents frequently spoke about the "golden hour" of appointments, which is the time immediately after the school day is over but before when offices commonly close at 5 pm. These appointments are incredibly challenging to get. Parents frequently have to take time off from work, pull their children from school, or otherwise disrupt major obligations they and their children have to get services for their child. These scheduling issues add another layer of stress for families, and often contribute to delays in their children accessing care.

> *"I did have to take him out of school and change my schedule to get him in for therapist appointments. There aren't enough appointments after school. As a single parent providing the income, that makes it hard to make ends meet."*

Parents' familiarity with the system improves their family's experiences and child's outcomes.

Children with an older sibling on the autism spectrum or with another disability benefit from their parents knowing how to navigate the system. Parents are familiar with the steps they need to pursue and how the system is structured overall, even when their older child experienced a different health need. However, this benefit can be erased when parents move to a different state, or even counties within Minnesota, as processes and resources available differ widely across geographies.

Paperwork is overwhelming, both logistically and emotionally.

Parents must maintain an incredible amount of organization and attention to detail throughout the system of supports. Paperwork was often mentioned to be confusing, overwhelming, and emotionally difficult for parents. Parents frequently spoke about having to repeatedly go over all the ways their child is atypical or "failing," which can be demoralizing and overwhelming to parents.

> *"I get upset when I think about the paperwork. To this day we still have a lot of paperwork, he's only been diagnosed for a year, but I'd say what's hard is that 99% of the papers is, what's different about your child, and I hate to say this, but what's wrong with your child, why aren't they doing X Y Z, and there's only one question about what you love about your child, what characteristics or whatever. It would be nice if there was a little more positivity, I know that defeats the purpose of getting your child help. Knowing this was most likely going to be his outcome, I can't imagine being a parent for the first time and filling out that paperwork."*

SYSTEM-WIDE REFLECTIONS

We asked parents a series of questions for them to reflect on the entire journey their family had been on to get services for their child or children with autism. These were questions about whether or not they got all the resources they need, what resources they turned to when they did not know what to do next, and their thoughts on why a family might drop out or stop pursuing treatment and supports for their child or children with autism. The following section summarizes the key themes we heard.

Key themes

Parents receive little navigation support and primarily rely on themselves and other parents of children with autism.

We asked parents who they turned to when they did not know what to do or where to go next. Parents commonly expressed that they had to do a substantial amount of research on their own with no one helping them. Parents spoke about absorbing as much information as they could through the internet, books, pamphlets from local doctors' offices, and any other place they could capture information.

When parents did get information from others, it was most frequently from other parents of children with autism. They commonly met these parents through social media, oftentimes Facebook groups specifically for parents of children with autism. Many parents noted that if there is one thing parents should turn to once their child is diagnosed, it is social media. However, parents also spoke about being overwhelmed by the amount of information and misinformation they were exposed to on social media, as well as having to deal with the intense emotions of other parents while trying to process their own feelings.

Parents also turned to people with knowledge of the system who can help them navigate. This often was a medical professional or school staff member, but included a wide variety of professionals working within the system. Because they had built a positive relationship with this professional over time, they felt comfortable going back to that person for resources, information, and advice, even if their question was outside of the actual scope of their profession or role.

Parents strongly benefited from having people in their personal networks with knowledge of the system. Because these people know the family, they have a personal interest in suggesting services and supports that might be useful for the family.

Many parents we spoke to had worked within the system at some point, for example as an educator, nurse, or a county employee. By working within the system, these parents benefited from the training and experience they had gained on the other side of the system; they could use that knowledge to access to services and supports once they needed them for their family. However, even these parents who have direct professional experience working in the system noted that they struggled to understand and fully access the system.

Still, many respondents noted that they really did not have consistent resources to turn to, and that they had to quickly learn as much as they could about autism, the services available within Minnesota and in their county, therapeutic supports, and health insurance. They frequently learned information in a piecemeal fashion and had to draw connections between the stages themselves. Parents commonly discussed the stress and exhaustion that came from having to independently learn as much information as possible without clear guidance.

Parents said stress and barriers to care are primary reasons why families would drop out of the system.

We asked parents to discuss why families might give up or drop out of the system. Common responses included:

- Feeling overwhelmed by caregiving responsibilities to the extent that they have no bandwidth to continue to fight for services
- Not knowing what is available to them, not being able to get clear information and referral to services they need unless they ask for the "right" thing
- Challenges associated with provider shortages, including distance to providers and wait times to be seen
- Paperwork and red tape to access care; lack of communication and follow-through by providers or the county
- The cost of care when on private insurance
  - Barriers to accessing Medical Assistance to alleviate those costs
- In some cases, not seeing positive outcomes or results for their child, and other cases, having to deal with the child's resistance to the service
- Challenges balancing work and caregiving
  - The intensive involvement and time commitment required for ABA and other therapeutic interventions
- Dismissiveness from professionals in the system

Even beyond the benefits to children with autism and their families, the Department of Human Services and their system partners benefit from children with autism receiving early intervention. It is critical to address the rationale for families to drop out to improve the quality of life and well-being of families of children with autism, and also to ensure that children with autism grow to live meaningful lives within the community.

The Department of Human Services and other stakeholders should consider the following recommendations to prevent drop-outs:

- Find ways to reduce parental and family stress, including:
  - Providing greater system navigation assistance
  - Streamlining paperwork obligations
  - Increasing the number of providers across the system
  - Proactively offering services and supports
- Increase training for professionals in the system, including:
  - Pediatricians, primary care doctors, and other health care professionals around the signs and symptoms of autism and how to suggest further screening and assessment. Specialists should receive training on how conditions they see may tie back to an autism diagnosis.
  - School administrators and staff around their obligations to create IEPs with accurate autism determinations and follow the plan set forth in the document.
  - Case managers around the various services and supports available to families of children with autism and how they should proactively suggest these to parents.

- Consider ways to decrease out-of-pocket expenses for families, including:
  - Increasing awareness of MA and TEFRA
  - Revisiting the sliding scale fees attached to TEFRA
  - Working with the state legislature to pressure private health insurance companies to provide greater coverage for autism-related services

Parents requested more support and streamlining of the system.

We asked parents for one suggestion they had to improve the service system for families of children with autism. We offer more detailed considerations in each of the system phases above; here, we summarize parents' high-level suggestions.

- **Enhance navigation assistance,** through resources like a flow chart of where parents should go next and help from professional navigators. This was the most frequently mentioned way to improve the system.
- **Improve communication and collaboration** between phases to allow for more consistent and complementary care for children with autism.
- **Improve parental support and education** to provide parents with the information they need to access care and staff who can better support parents navigating the system.
- **Increase consistency across counties** or at the state level. This includes more systematic ways of providing services, and more consistent paperwork and resources.
- **Improve paperwork and assessment processes.** Parents were frustrated by continuously proving their child's lifelong disability, keeping vast amounts of documentation and paperwork, and keeping track of county staff and other professionals who lose families' paperwork.
  - Parents were especially frustrated when discussing how bureaucratic paperwork delays make an impact on their child's progress. Delays in paperwork processing can keep children from receiving services during the window of time in which it is most important.

> *"When people do an assessment of a child with autism, it'd be good to give them a myth vs. fact document, some information as you're waiting to have the assessment done. So then you can sort through some things in advance. More reputable things, even a map of some of the things you might want to consider if your child does have a diagnosis of autism. To know that in advance sometimes helps so you know what questions to ask and helps you understand the assessment better."*

- **Raise awareness about the services available before medical diagnosis.** Education and outreach about the importance of early intervention seems to have been effective. However, parents are often stuck on wait lists for the diagnostic assessment that is necessary to access services.
- **Support information sharing and knowledge translation with parents of children with autism.** Parents often spoke about how luck is what has gotten their family services and supports they need: they happened to talk with the right parent at the right time to learn about different services, or they happened to call a professional who was particularly helpful, or otherwise got information by happenstance. Because of this, parents do not feel in control of the services and supports their family accesses, which can be stressful and demoralizing.

> *"I didn't realize what I was doing with Help Me Grow. I thought it was just someone else who could give me information. I didn't know this would open so many doors for him. I was really grateful that it did. If I hadn't accepted the offer for us to work with them, it could have gone so differently for our son and for my family."*

- **Support more communication and different methods of communication** between parents and professionals working within the system. Multiple methods of communicating with providers would be helpful for parents, as well. Relying solely on phone calls is particularly challenging for parents juggling workplace responsibilities and schedules.
- **Recruit and retain autism providers, case managers, and other professionals across the system** to ensure better access to services and supports. Provider shortages were a challenge across the system of supports.

Experiences accessing services and supports in other states

We heard a wide variety of feedback from parents about their experiences with accessing services and supports in other states. Some parents lived in another state in the early stages of their family's journey; many parents had positive experiences with professionals in the system during the initial stages of identifying signs of autism and getting a medical diagnosis of autism.

After the diagnosis, several parents discussed moving to Minnesota from other Midwestern states because of the types of services and supports available to families of a child with autism. Notably, many parents discussed the availability of autism centers in Minnesota, which they did not find in their home states. Some parents had considered moving to other states to be closer to family or for employment opportunities, but decided to stay in Minnesota to ensure their family still had access to the services and supports available here.

> *"We had some evaluations at the local clinic in anticipation of the move to high school [in Wisconsin]. And as we sat in the office getting the low down on what we were going to be working with the schools. I looked at [the health care providers] and I said 'so let me ask. We have the option of moving to Rochester.' And they looked at each other and they didn't say a thing. And they looked back at us and one of them said, 'oh, we'd be looking at [moving to] Rochester [if we were you.]' We were like, 'Ok. Done.'"*

Impact of the COVID pandemic

Due to the COVID pandemic, a shelter-in-place order was ordered for the state of Minnesota three weeks before data collection began for this study. Many organizations and families had chosen to stay home and limit interactions with others in the weeks leading up to the official shelter-in-place order. Families of children with autism face unique challenges related to social isolation. The following are some of the key themes from parents' discussions of how this pandemic and resulting quarantine has made an impact on their families.

While this pandemic is a special event, there are ways the service system can learn from these issues and potentially make permanent changes even as things return to a "new normal." We offer some key themes and considerations below.

Key themes

- **Loss of routine.** Children with autism generally crave routine. COVID fundamentally shifted the ways in which people operate within their communities, forcing families to stay home from work, school, and other activities that are a part of a consistent routine. While this has been incredibly challenging for everyone, children with autism and their families are particularly affected. Parents often spoke about their children having more meltdowns and feeling more depressed and anxious when discussing the impact of COVID on their families.
- **Lack of access to therapy.** Children across the spectrum benefit from therapy of various sorts, from intensive therapeutic supports like ABA therapy provided at an autism center to talk therapy with a psychologist. Parents discussed how the shelter-in-place order greatly limited their access to therapy. Parents often spoke about trying to prevent a loss of skills during this time; the goal was often to maintain the progress that therapy had built previous to the shelter-in-place order.
- **Shifting to telehealth.** Therapists and other service providers increased their capacity to provide care through telehealth services. Parents noted that telehealth services are not as effective as in-person care, but were grateful for the opportunity to have professional support for their children to prevent a decline in skills and to provide support during a time of heightened stress for all. Telehealth appears to work better for some children with autism; children with autism who do not have an intellectual disability seem to be better equipped to use teleconferencing services than children with autism who do. Because telehealth also offers opportunities to address some of the provider shortage issues we face in Minnesota, additional consideration should be given for how to customize or modify telehealth approaches to work for children with autism and their families.
- **Shifting to online learning.** Similar to telehealth, online learning works better for some children with autism than others. Autistic children with intellectual disability are particularly helped by in-person instruction from a special education teacher; this shift to online learning is especially difficult for this community.

Considerations

We do not yet know how society will change in the wake of the COVID pandemic. Hopefully, our service systems and communities are able to learn and grow from this experience to be able to provide better care for children with autism even without in-person services. The Department of Human Services and its partners worked quickly to ensure families are receiving the best care possible in light of the pandemic. We encourage these partners to collaborate with one another during this evolving situation and once we are past it to discuss key learnings and identify what permanent shifts should occur. Some considerations include:

- Consider ways to increase telehealth and teletherapy services going forward as a permanent option for families who are served well by this approach, as mentioned above.
- Determine ways for special education services to continue to be provided during distance learning.
- Address the increased social isolation of parents of children with autism, including expanding the use of online support groups, considering a mentorship program as mentioned above, and finding other ways to connect families of children with autism with one another.

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Appendix

- EIDBI Key System Touch Points
- DHS EIDBI Journey Mapping: Family Interview Protocol
- EIDBI Journey Mapping: Key Informant Interview Protocol for SYSTEM STAKEHOLDERS
- Family Interview Codebook

EIDBI Key System Touch Points

1. Awareness of developmental milestones

2. Questions on developmental milestones

- Parent/caregiver, health care provider, or school staff identified a need for autism evaluation or additional screening
- Referral for additional assessment, evaluation, and screening

3. Medical Diagnoses

- DA Assessment
- CMDE

4. Initial screening and assessment

- Make an appointment, with primary care.
- Developmental history and exam
- Developmental screening
- Referral to psychology, developmental pediatrics, or other specialist for diagnostic assessment
- Provider calculates the results/scores the assessment
- Doctor or social worker communicates results to family
- Follow Along program
- Child and Teen Check up

5. Educational identification

- Special education evaluation is requested by parent/caregiver and/or school staff
- Parent/guardian gives consent for evaluation
- Results are communicated to the family

5A) Education services (ages 0-21 years)

Community Education Resources:

- Help Me Grow
- Early Childhood Family Education (ECFE) program (typically 0-5 years)
- Head Start (Pre-K)
- Preschool (ages 3-Kindergarten)
    i. Public school district, private, and community pre-schools

Special Education—Pre-K:

- Individual Family Service Plan (IFSP--ages 0-3)—assistive technology, hearing/vision testing, home visits, occupational, physical, and speech therapies
- Early Childhood Special Education (ECSE)—ages 3 to Kindergarten.
    i. Individualized Education Plan (IEP) is created
    ii. Services provided with a school or community-based preschool

Special Education (K-12)

- K-12 Special Education Services
    i. Assistive technology
    ii. Direct instruction in core areas
    iii. Home visits
    iv. Occupational Therapy (OT), Physical Therapy (PT), and Speech Language Pathology (SLP)
- Service coordination and community referrals
- Transition services for school
    — Vocational Rehabilitation Counselors

6. Health care

6A) Private Insurance- identify what services are and are not covered

6B) Medical assistance (MA/Minnesota Care)

- MNSURE
- Tax Equity and Fiscal Responsibility Act (TEFRA) (for children under 18 years old)
- Disability determination process (state of Minnesota **or** Social Security Administration)
- Pre-paid health plans
- Medical Assistance programs for adults with disabilities

7. EIDBI/CTSS (CMDE is needed to establish medical need)

Early Intensive Developmental and Behavioral Intervention (EIDBI)

- Individual and Group Intervention (ABA/DIR)
- Enrolled in MA, Minnesota Care, TEFRA, or other programs
- Family/caregiver training and counseling

Children's Therapeutic Services and Supports (CTSS)

- Psychotherapy
- Skills training
- Day Treatment
- Crisis Services
- Case management services

Case Management

8. Continued supports (accessed through a hospital or clinic)

- Well-child checkups
- Occupational therapy
- Physical therapy
- Speech and Language Pathology
- Medications
- Mental health services
    — Individual therapy
    — Family therapy
    — Crisis therapy
- Services for co-occurring conditions
- Other referrals and services:
    i. Seizures
    ii. Sleep problems
    iii. Dietary/nutritionist

9. MN Choices assessment (annual re-assessment)

- Determine eligibility
    — Determines what services may be beneficial

10. Waivers and other supports

- Home and Community Based Waivers (HCBS) including Consumer-directed community supports (CDCS)
- PCA
    — Consumer Support Grant (CSG) where available
- Waiver services
    — Housing
    — Supplies
    — Transportation
    — Case management
    — Equipment
    — Employment
- Family Support Grant (FSG)
    — Financial assistance for services and goods
    --- Cannot be on a waiver
    — Need to go through State Medical Review Team (SMRT) process to access this assistance

11. Community services and supports available throughout the life span based on need (ages 14 and up)

- Waiver services (for those who qualify based on a MN CHOICES assessment)
    i. Case management
    ii. Employment
    iii. Equipment and supplies
    iv. Transportation
- PCA
- Employment Services
- Home care nursing
- Home health aide
- Independent living
- Postsecondary education (after High School)

12. Other organizations (ongoing involvement)

- Family Voices
- The Arc
- Parent Advocacy Coalition for Educational Rights (PACER)
- Autism Society of Minnesota (AUSM)
- Minnesota Disability Law Center

13. Other resources/materials (ongoing involvement)

- EIDBI 101 training
- Facebook/social media support groups
- Self-advocates and Advocates
- AUSM
- Word of mouth
- Parent groups
- Others?
- MN Autism resource portal MN.Gov/autism

DHS EIDBI Journey Mapping: Family Interview Protocol

Introduction (5min.)

Hello! My name is ____________ (name of interviewer). I am from Wilder Research. Wilder is working with the Minnesota Department of Human Services to learn more about the experiences families have when their child is identified to be on the autism spectrum. With your help, it will help us try to help make our policies and systems more accessible for all.

Is this still a good time?

- If **yes**, continue
- If **no**, thank them for their time and end the interview and reschedule and record on respondent sheet

This interview will take about an hour and fifteen minutes of your time, depending on how much you have to say. I understand this is a lot to ask for your time and commitment. As a thank you, we will send you a $30 Target gift card. All of the information you share with us is confidential—we will not share this with anyone outside of the research team and your name will not be associated with any of your responses in any report that we write. Additionally, this interview is voluntary and your decision whether or not to participate will not affect any services you may be receiving through the Minnesota Department of Human Services or any of their other partners.

We want to learn more about the families' experiences and journeys. We would like to know the different programs, services, and professionals they encounter as they navigate the system to get services for their child. We are talking with families across the state including Twin Cities Metro area residents, people who live in Greater Minnesota, people who speak Hmong, Somali, or Spanish as their primary language, as well as African American families and families who are American Indian. This information will be used by the Minnesota Department of Human Services and other partners in the system to address gaps and needs with the goal of improving the experiences and outcomes for children and families from your community.

We would like to record this interview. The recording will be destroyed after it is transcribed. Is that okay? **YES NO**

We want to understand families' experiences as they are attempting to get services for their children. For this project, we are focusing on families with children who are ages birth through age 21.

INTRO_Q: To get started, could you provide me with your name, the age of your child who is on the spectrum, and at what age they were identified?

Key System Touch Points

Next, we are going to ask you to please tell us about your experiences with the system that you may have encountered starting from when your child was identified as potentially being on the autism spectrum, and extending through the child's early years of young adulthood. Note that these programs, services, interventions, and professionals may not occur in the order we talk about them—we understand that everyone has a different journey. We also understand that some of these things we mention will happen at the same time or be an ongoing part of the child's and families' lives. Also, not all families may have encountered each one of these things.

NOTE: If at any point in this interview a participant is confused about a particular term, you could ask PROBE: How would families refer to this touchpoint in the system? What words/phrases do they use for this?

NOTE: If families do not have experience with a particular phase in the system, for example if they have young children under age 14, they will most likely not have encountered the services in that phase. If that is the case, please skip asking questions for that phase.

I will now describe each phase of the journey and the programs, services, resources, and professionals in the system that you may have encountered in each of the phases. The first phase we will talk about is:

Phase 1-2: Awareness and Questions on Developmental Milestones. This is when:

- You recognized there was a need for an evaluation or additional screening for your child
- A referral for additional assessment, evaluation, or screening happened by a provider

1. How would you rate your families' experience during this phase: excellent, good, fair, poor, or terrible? Why did you rate it this way?
    a. What are some good things about your family's experiences in this phase?
    b. What or who helped your family the most in this area? PROBE: Professionals in the system? Family? Friends? Community members? Support groups/other families who have a child who has autism?
2. What are some things that were challenging about your family's experience as you were searching for answers?
    a. What are the barriers your family experienced in trying to seek help and get your questions answered?

Phases 3-4: Medical Diagnoses and Initial Screening and Assessment. In this phase, your child may have received:

Medical Diagnoses – a tool to determine by the child's doctor that they are on the spectrum

- A diagnostic assessment, also called a DA Assessment
- A comprehensive multi-disciplinary evaluation or a CMDE

Initial Screening and Assessment

- Family makes an appointment with primary care provider
- Developmental history and exam of the child
- Developmental screening
- Referral to psychology, developmental pediatrics, or other specialist for diagnostic testing
- Provider calculates the results/scores the assessment
- Provider or social worker communicates results to the family
- Follow Along program
- Child and Teen Check Ups

1. How would you rate your families' experience during these phases: excellent, good, fair, poor, or terrible? Why did you rate it this way?

    a. What are some good things that happened during this phase?

    b. What or who helped you the most during your child's medical diagnosis and initial screenings and assessments? (PROBE: Professionals in the system? Family? Friends? Community members? Support groups/other families who have a child who has autism?)

2. What are some things that were challenging about your experience with getting a medical diagnosis for your child?

3. What are the barriers your family experienced in trying to get a medical diagnosis or getting your child screened and assessed for ASD?

4. Did you feel like the provider gave you enough information on what to do next? Is there any feedback you would like to share with us about your process?

Phase 5-5A: Educational identification and services. During this phase:

- Educational identification occurs:
    - Special education evaluation is requested by parent/caregiver and/or school staff
    - Parent/guardian gives consent for evaluation
    - Results are communicated to the family

- Education services begin and continue for children ages 0-21
    - **Community Education Resources, including:**
        - Help Me Grow
        - Early Childhood Family Education (ECFE) program (typically 0-5 years)
        - Head Start (Pre-K)
        - Preschool (ages 3-Kindergarten)
            - Public school district, private, and community pre-schools

- **Special Education—Pre-K**
  - Individual Family Service Plan (IFSP--ages 0-3)—assistive technology, hearing/vision testing, home visits, occupational, physical, and speech therapies
  - Early Childhood Special Education (ECSE)—ages 3 to Kindergarten.
    - Individualized Education Plan (IEP) is created
    - Services provided with a school or community-based preschool
- **Special Education (K-12)**
  - K-12 Special Education Services
    - Assistive technology
    - Direct instruction in core areas
    - Home visits
    - Occupational Therapy (OT), Physical Therapy (PT), and Speech Language Pathology (SLP)
  - Service coordination and community referrals
  - Transition services for school
    - Vocational Rehabilitation Counselors

1. How would you rate your families' experience during this phase: excellent, good, fair, poor, or terrible? Why did you rate it this way?

   a. What are some good things about these programs, services, and resources?

   b. What or who helped your family the most in this area?

2. What are some things that were challenging about the experience with your child's educational identification and educational services provided?

3. What are the barriers your family experienced in trying to access these programs, services, and resources for your child?

Phase 6: Health care (including private insurance and Medical Assistance (MA/Minnesota Care). In this phase:

- Families identify types of services are covered or not covered by private insurance, and/or
- Enroll in Medical Assistance (MA/Minnesota Care)
  a. MN-SURE
  b. Tax Equity and Fiscal Responsibility Act (TEFRA) (for children under 18 years old)
  c. Disability determination process (state of Minnesota **or** Social Security Administration)
  d. Pre-paid health plans
  e. Medical Assistance programs for adults with disabilities

f.

1. How would you rate your families' experience during this phase: excellent, good, fair, poor, or terrible? Why did you rate it this way?

2. What are some good things about these programs and resources?

3. What or who helped your family the most in this area?

4. What are some things that were challenging about your family's experiences with these programs and resources?

5. What are the barriers your family experienced in trying to access these programs and resources?

Case management services:

This could include children's mental health case management, developmental disabilities case management, waiver/CADI/CDCS case management, rule 185 case management, youth behavioral health or targeted case management.

- What type(s) of case management did your family access?

- How would you rate your families' experiences with case management: excellent, good, fair, poor, or terrible? Why did you rate it this way?

- What are some good things about case management?

- What or who helped your family the most?

- What are some things that were challenging about your family's experiences with case management?

Phase 9-10: MN Choices assessment (annual re-assessment) and waivers and other supports. In this phase, families get help with:

MN Choices Assessment

- Determine eligibility for supports and services. For example, types of home and community-based services your child may need. This could also include waiver services such as a PCA, specialized equipment, respite care, and others.
- Determines which services may be beneficial for children and families

Waivers and other supports

- Home and Community Based Waivers (HCBS) including Consumer-directed community supports (CDCS)
- PCA
    - Consumer Support Grant (CSG) where available

- Waiver services, including Consumer Directed Community Supports (CDCS)
    - Housing
    - Supplies
    - Transportation
    - Case management
    - Equipment
    - Employment

- Family Support Grant (FSG)
    - Financial assistance for services and goods
    - Cannot be on a waiver
    - Need to go through State Medical Review Team (SMRT) process to access this assistance

[Ask if their family has gone through this phase.]

1. How would you rate your families’ experience completing the MN Choices assessment and/or accessing waiver services and other supports: excellent, good, fair, poor, or terrible? Why did you rate it this way?

2. What are some good things about completing this assessment and accessing waiver services and other supports?

3. What or who helped your family the most in this area?

4. What are some things that were challenging about your experience with completing the MN Choices assessment and accessing waivers and other supports?

5. What are the barriers your family experienced in trying to complete the assessment and accessing waiver services and other supports?

Phase 7: Early Intensive Developmental and Behavioral Intervention and Children’s Therapeutic Services (EIDBI/CTSS). In this phase:

Note: A CMDE is conducted to determine eligibility for EIDBI. A Diagnostic Assessment (DA) provides a medical diagnosis and is needed in order to authorize CTSS services.

Early Intensive Developmental and Behavioral Intervention (EIDBI)

- Individual and Group Intervention (ABA/DIR)
- Enrolled in MA, Minnesota Care, TEFRA, or other programs
    - Family/caregiver training and counseling

Children's Therapeutic Services and Supports (CTSS)

- Psychotherapy
- Skills training
- Day Treatment
- Crisis Services
- Case management services

[Ask if their family has gone through this phase.]

1. How would you rate your families' experience during this phase: excellent, good, fair, poor, or terrible? Why did you rate it this way?

2. What are some good things these benefits and support services provide?

3. What or who helped your family the most?

4. What are some things that were challenging about your family's experience with these benefits and support services?

5. What are the barriers your family experienced in trying to access these benefits and support services?

Phase 8: Continued supports (accessed through a hospital or clinic). This phase includes:

- Well-child checkups
- Occupational therapy
- Physical therapy
- Speech and Language Pathology
- Medications
- Mental health services
    a. Individual therapy
    b. Family therapy
    c. Crisis Therapy
- Services for co-occurring conditions
- Other referrals and services, such as seizures, sleep problems, dietary/nutritionist

[Ask if their family has gone through this phase.]

1. How would you rate your families' experience during this phase: excellent, good, fair, poor, or terrible? Why did you rate it this way?

2. What are some good things about these services, supports, and resources?

3. What or who helped your family the most in this area?

4. What are some things that were challenging about your family's experience with these services, supports, and resources?

5. What are the barriers your family experienced in trying to access these services, supports, and resources?

Phase 11: Community services and supports available throughout the life span based on need (ages 14 and up). This includes:

- Waiver services (for those who qualify based on a MN Choices assessment)
    a. Case management
    b. Employment
    c. Equipment and supplies
    d. Transportation
- PCA
- Employment services
- Home care nursing
- Home health aide
- Independent living
- Postsecondary education (after high school)

[Ask if their family has gone through this phase.]

6. How would you rate your families' experience during this phase: excellent, good, fair, poor, or terrible? Why did you rate it this way?

7. What are some good things about these services, supports, and resources?

8. What or who helped your family the most in this area?

9. What are some things that were challenging about your family's experience with these services, supports, and resources?
10. What are the barriers your family experienced in trying to access these services, supports, and resources?

Phase 12, 13: Services and support from other organizations and resources.

Other organizations you may have interacted with:

- Family Voices
- The Arc
- Parent Advocacy Coalition for Educational Rights (PACER)
- Autism Society of Minnesota (AUSM)
- Minnesota Disability Law Center
- EIDBI 101 Training
- Facebook/social media support groups
- Self-advocates and Advocates
- Parent support groups
- MN Autism Resource Portal (MN.gov/autism)

- How would you rate your families' **overall** experiences with these organizations and resources: excellent, good, fair, poor, or terrible? Why did you rate it this way?

- What are some good things about these organizations and resources? What or who helped your family the most?

- What are some things that were not so good about your family's experience with these organizations and resources?

- Were there other resources and supports that we did not talk about that your family found helpful? What resources and supports have been the most beneficial to your child and/or family or had the most impact on your lives?

Other questions

Now we'd like to give you the opportunity to comment further on each of the phases and touchpoints in case we haven't yet covered something that's important to include in our report.

Q1: In your opinion, are these **all** of the phases and key touch points that families experience? Which phases are we missing?

Q2. Did your family get access to all of the resources and supports you needed for your child?

a) If yes, what helped you get access to these?

b) If not, what other things did you need but did not receive?

Q3. From your experience, what things might cause a family to give up, drop out, or not continue with any of the services for their child who is on the autism spectrum? Why?

Q4. Who or what resources did you turn to when you got stuck and did not know where to go next?

Q5. What, if anything, do you think is the most important improvement that could be made to the service system for families of children who are on the autism spectrum in order to best meet their needs?

Q6. Do you have anything else you'd like to add that we haven't discussed already?

Demographics

Now, we'd like to know a little more about you. Remember, everything you tell us is confidential – we're just asking for a little demographic information to better understand who's participated in our study.

Q1. What's your age?

Q2. What's your zip code?

Q3. How do you identify your race and ethnicity? [Interviewer: highlight identified categories]

- ☐[1] American Indian, Native American or Alaska Native
- ☐[2] Asian American or Asian
- ☐[3] Black, African American or African
- ☐[4] Hispanic or Latinx
- ☐[5] White or Caucasian
- ☐[7] Prefer not to answer

Q3b. What's the race and ethnicity of your child? [Interviewer: highlight identified categories]

- ☐[1] American Indian, Native American or Alaska Native
- ☐[2] Asian American or Asian
- ☐[3] Black, African American or African
- ☐[4] Hispanic or Latinx
- ☐[5] White or Caucasian
- ☐[7] Prefer not to answer

Q4. How do you identify your gender? [Interviewer: highlight identified category]

- ☐1 Female
- ☐2 Male
- ☐3 Another way, please describe: _______________
- ☐7 Prefer not to answer

Q4b. What's the gender identity of your child? [Interviewer: highlight identified category]

- ☐1 Female
- ☐2 Male
- ☐3 Another way, please describe: _______________
- ☐7 Prefer not to answer

Gift cards, thank you

Thank you very much for your time and the information you provided today. We will be sharing the results of these interviews families in a report and a visual journey map in June 2020.

Where would you like your $30 Target gift card sent (please anticipate up to a 2-week delay in the shipment of Target gift cards)?

Name:___________________________________

Address:__________________________________

Phone number (in case there is an issue):_______________________________________

Would you like a copy of the report? Y/N

[IF YES]: Email address: _____________________________________

RESOURCES

If you have any questions, or need more information, please visit: https://mn.gov/autism/

EIDBI Journey Mapping: Key Informant Interview Protocol for SYSTEM STAKEHOLDERS

Introduction (5 minutes)

NOTE TO INTERVIEWER: PLEASE EMAIL THE KEY TOUCH POINTS DOCUMENT TO THE RESPONDENT PRIOR TO THE INTERVIEW.

Hello! My name is _____________ and I work for Wilder Research. We are working with the Minnesota Department of Human Services to learn more about the experiences families have when their child is identified to be on the autism spectrum. This interview will take about an hour. Is this still a good time?

If **yes**, proceed.

If **no**, thank them for their time, end the interview, and record in the sample file as a refusal.

We are interested in learning more about the path families take and touch points[1] they encounter as they navigate the system to get services for their child. We are talking with families throughout the state of Minnesota and focusing on Hmong, Somali, or Spanish as their primary language, as well as African American families and families who are American Indian. We want to ultimately identify the high points and low points families experience as they are as they are receiving information about and connecting to supports and services for their child. For this project, we are focusing on children who are ages birth through age 21.

I am contacting you because you were identified as someone who is knowledgeable about the current system and the touchpoints that families encounter when navigating the system by staff at the Minnesota Department of Human Services. We will also gather input from families who have a child who is on the autism spectrum, so if you also have experiences as the parent of a child who is on the autism spectrum, feel free to let us know if you want to share that.

Your decision about whether or not to participate and your responses to the interview questions will not affect your relationship with the Minnesota Department of Human Services or Wilder Research. Your responses are confidential and when we report these results from the interviews, we will not report your name and we will combine all responses of others. We would like to record the discussion we have today so we do not miss anything in our notes. The recording will be deleted after the notes are finalized. Is that okay with you?

QUESTIONS

Next, we are going to ask you about the key touch points that families may experience in their journey from finding out their child is on the autism spectrum through when they begin to access services in young adulthood. We've sorted these into groups of touchpoints. Note that these touch points may not occur in the numerical order we've presented and we understand that some of these will happen at the

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[1] A system touch point is any encounter where users or potential users engage with the system to exchange information, provide services, or handle transactions.

same time or be an ongoing part of the child's and families' lives. After I'm done listing these, we're going to go over some specific questions about the touchpoints and your specific role in the system. Please refer to the document we emailed you, which lists each of the touchpoints.

First, we're going to ask a little bit about your role in this system, and then we are going to give you the opportunity to comment on each of the phases and touchpoints we just discussed.

1) Please describe where you work and your role in helping families with children who are on the autism spectrum. In the phases and key touch points we just discussed, which of these are you involved in?

2) At what point in the journey we just described do you first make contact with families (or do they first contact you)? How do these families get referred to you and by whom?

3) In your opinion, did we accurately list all of the phases and key touch points with the system that families experience when navigating the system to get assistance for their family member who is on the autism spectrum? What, if anything, are we missing?
PROBE: How would families refer to these touchpoints in the system? What words/phrases do they use for each of these touch points?

4) How do families get to the key touchpoints that you are involved in with this system?

5) What types of support, experiences, or services are families supposed to get from each touchpoint in your part of the system?

6) How often does your part of the system collaborate or interact with the other parts of the system? For what purposes? What are the successes as far as collaboration across different system touch points? What are the challenges?

7) How do you know that a family is successfully moving through your part of the system?

8) From your perspective, what do you think are the easiest touch points in your part of the system for families to navigate?

9) What barriers or challenges do families encounter in each touch point in your part of the system?

10) What, in your experience, causes families to give up, drop out, or not continue with any of the services for their family member who is on the autism spectrum in your part of the system?

11) How would you know if a family was experiencing challenges navigating this part of the system? In your opinion, what resources or people do families turn to when they are stuck or do not know where to go? Are there any mechanisms in place that help families to get back on track if they are struggling? Do these work? What could be changed about these to ensure they work better for families?

12) We know that families can sometimes face challenges in their daily lives such as difficulty accessing housing, food, or public benefits, obtaining medical or health insurance, or getting reliable transportation, and other barriers. Do you observe any of these needs in the families you work with? What are the impacts (if any) of these barriers on families' ability to successfully move through the system? What, if anything, does your part of the system do to address these needs or barriers?

    PROBE: How about specifically for underrepresented communities? Cultural obstacles (i.e. stigma? Interference with cultural practices?)? People of color and Indigenous communities? Non-English speaking communities? Families with children who have co-occurring conditions? Others?

13) Do you as a professional feel knowledgeable about all the different touchpoints and components for the system? Do you feel you have access to the information you need to support families? What resources or materials would help you support families better?

    PROBE: If you are a parent or caregiver of a child with autism, do you feel knowledgeable about the different touchpoints and system components? What resources do you need that would help you to understand the system better?

14) Do you have any additional final thoughts? Is there anything you would like to add that was not covered?

Thank you very much for your time and the information you provided today. We will be sharing the results of these key informant interviews and focus groups and interviews with families in a report and a visual journey map in summer 2020.

A) Would you like us to send you the report and journey map? YES NO

Family Interview Codebook

Meta-codes
A010: Phase 1 -2 – Awareness/Questions of developmental milestones
A030: Phase 3-4 – Medical diagnosis/screening and assessment
A050: Phase 5 – Educational identification and services
A060: Phase 6 – Health care
A065: Case management
A070: Phase 7 – EIDBI/CTSS
A080: Phase 8 – Continued supports (ABA, DIRFloortime, etc.)
A090: Phase 9 -10 – MN Choices Assessment, waivers, and other supports
A110: Phase 11 – Community services and supports
A120: Phase 12 – 13 – Other organizations and resources

A150: Journey Map review
A160: Family resources
A170: Resources turned to
A175: Rationale for drop-out
A180: System improvement
A200: Unclear phase

BC000: Positive experiences with orgs/people (general/others)
BC100: Negative experiences with orgs/people (general/others)

B010: Organization/professional (other)
B011: Advocacy organizations
B012: School staff
B013: Medical professionals
B014: Colleagues
B015: Family members
B016: Friends
B017: Social media – parent groups
B018: Social media - other
B019: County staff (General - such as case managers, benefits staff, etc.)
B020: MNChoices assessor
B021: Social worker
B022: Help Me Grow staff
B023: Other parents of kids with autism (not online)
B024: Autism center
B025: Therapists

C100: Positive interpersonal experiences – how they were positive (general/other)
C101: Information and resources
C102: Empathy/kindness
C103: Co-advocacy
C104: Qualified and knowledgeable providers/staff
C105: Helpful navigation of system

C200: Negative interpersonal experiences – how they were negative (general/other)
C201: Misinformation/misdiagnosis
C202: Unsupportive interpersonal approach
C203: Unsupportive or unwilling to implement interventions, organizational policy, or practice
C204: Professionals with little training/experience/knowledge
C205: Unhelpful with navigation of system
C206: In denial of diagnosis/identification

D000: System successes (general/other)
D010: Multi-disciplinary approaches
D020: Interconnected systems
D030: Therapy is working well/useful
D040: IEP is working well/useful
D050: Paperwork is manageable
D060: Paperwork is understandable
D070: Access to services
D080: Affordability of services
D090: Improved quality of life

E000: System difficulties and failures (general/other)
E005: System is difficult to navigate (general)
E007: Not knowing what's available/possible/"don't know what you don't know"
E010: Too much paperwork
E020: Confusing paperwork
E030: Staff turnover
E040: Inability to reach staff to discuss questions
E050: System silos (general/other)
E051: Lack of communication between providers/other professionals
E052: Data-sharing silos between providers/other professionals
E060: Health insurance coverage is confusing
E070: Services are too expensive/ not covered by insurance
E075: Medication is too expensive/not covered by insurance
E080: Access to care (general/other)
E081: Provider shortages (other)
E082: Waitlists/wait times/delays
E083: Distance to providers
E084: Lack of transportation to providers
E085: "Wait and see" guidance from professionals
E086: "Wait and see" guidance from non-professionals
E100: Different benefits/services, etc. by county
E200: Parent must have the "right" words, specifically ask for services/benefits
E210: Parent has to fight for their child/family
E300: School schedule/calendar difficulties

F000: Family stressors/emotions (general/other)
F005: Lack of time/scheduling difficulties (appointments, care, etc.)
F010: Disproportionate caregiving burden on one family member
F020: Reduction in work hours/leave workforce due to caregiving
F030: Overwhelmed/stressed
F040: Isolated
F050: Fearful
F060: Grief
F070: Experiences of racial bias from others
F080: Experiences of other forms of bias from others
F090: Gender roles/expectations
F100: Stigma of autism diagnosis
F110: Financial stress - general

G000: Journey Map review (general/other)
G100: Missing component
G200: Affirmation that Journey Map is correct

H000: Missing services/supports (general/other)
H100: School-based services/supports
H200: Therapeutic services/supports
H300: Medical services/supports
H400: Community-based supports

K000: Resources (general/other)
K100: Internet – general/other
K200: Books/articles

L000: Suggestions for system improvement (general/other)
L100: Increased training for school staff
L110: Increased training for medical professionals/therapists
L120: Changes to waiver policies
L121: Changes to medical policies
L122: Changes to educational policies
L123: Changes to other human services policies (beyond waivers)
L130: Improved communication with parents
L131: Improved education/training for parents
L132: Increased parent support
L135: Improved collaboration between phases/systems
L136: Navigation assistance

Z000: Flags
Z100: Flag – Quotable
Z150: Flag – Implications of COVID

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Wilder Research, a division of Amherst H. Wilder Foundation, is a nationally respected nonprofit research and evaluation group. For more than 100 years, Wilder Research has gathered and interpreted facts and trends to help families and communities thrive, get at the core of community concerns, and uncover issues that are overlooked or poorly understood.

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