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

JUNE 2020

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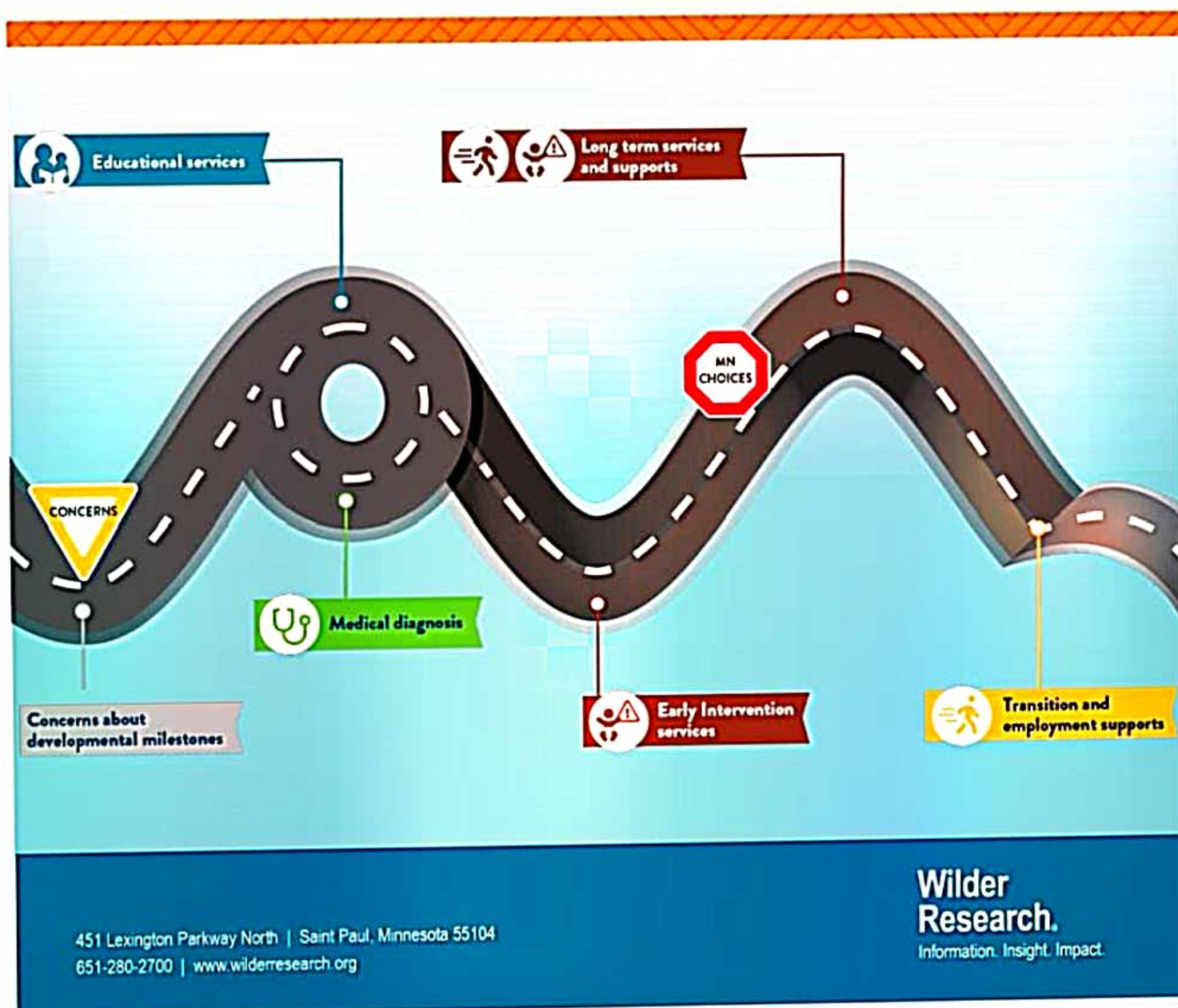
Introduction

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)
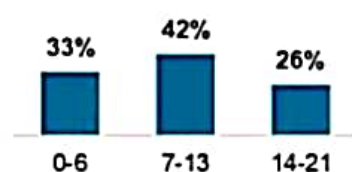
2. Child's age at diagnosis (N=86)
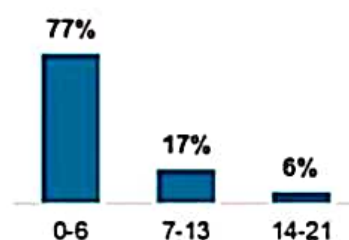
The vast majority of respondents identified as female (95%), while their child(ren) with autism were most commonly male (78%; Figures 3 and 4).

3. Parent gender (N=83)

■ Female ■ Male ■ Another gender identity

4. Child gender (N=88)

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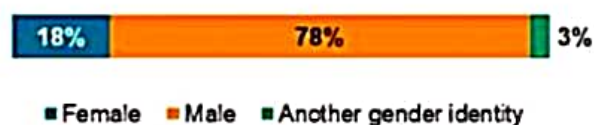
We asked respondents to indicate their racial/ethnic identity, as well as the racial/ethnic identity of their child or children who are on the spectrum. Respondents could select multiple racial/ethnic categories. Respondents and their children were predominately white (85% and 84%, respectively; Figure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

5. Race of respondents and children

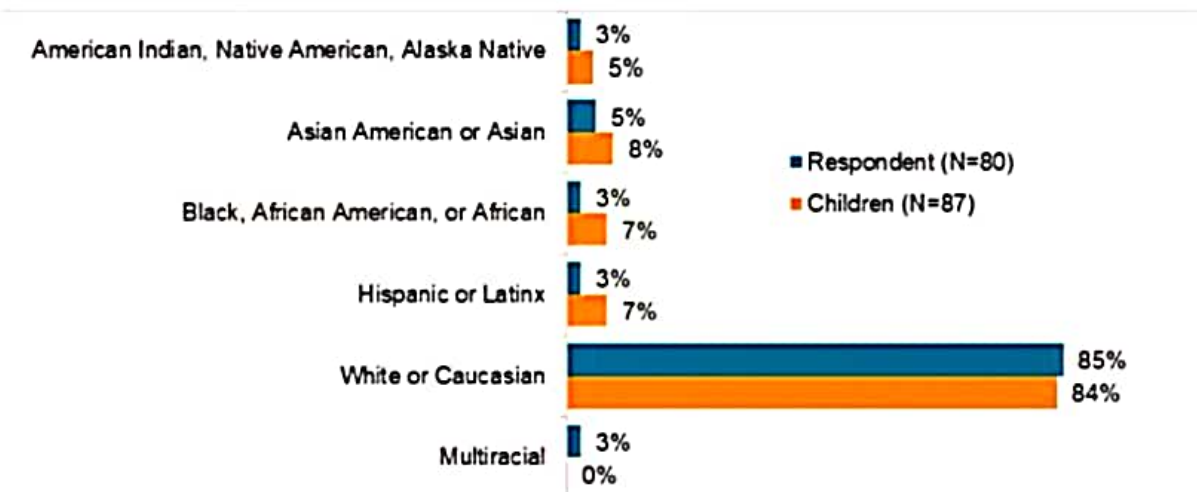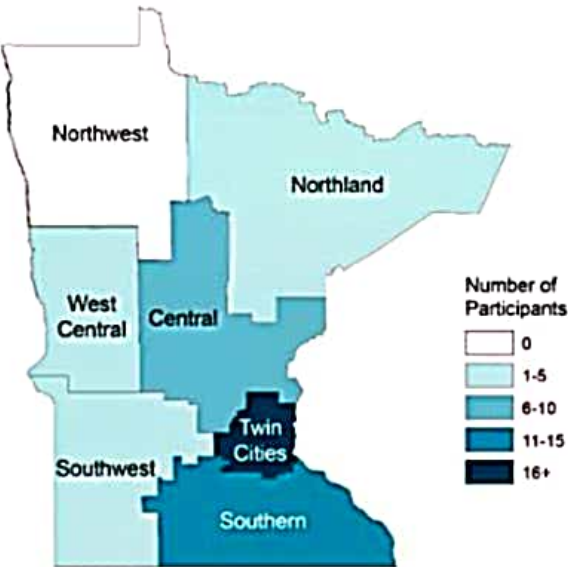| Race	Respondent (N=80)	Children (N=87)
American Indian, Native American, Alaska Native	3%	5%
Asian American or Asian	5%	8%
Black, African American, or African	3%	7%
Hispanic or Latinx	3%	7%
White or Caucasian	85%	84%
Multiracial	3%	0%

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.

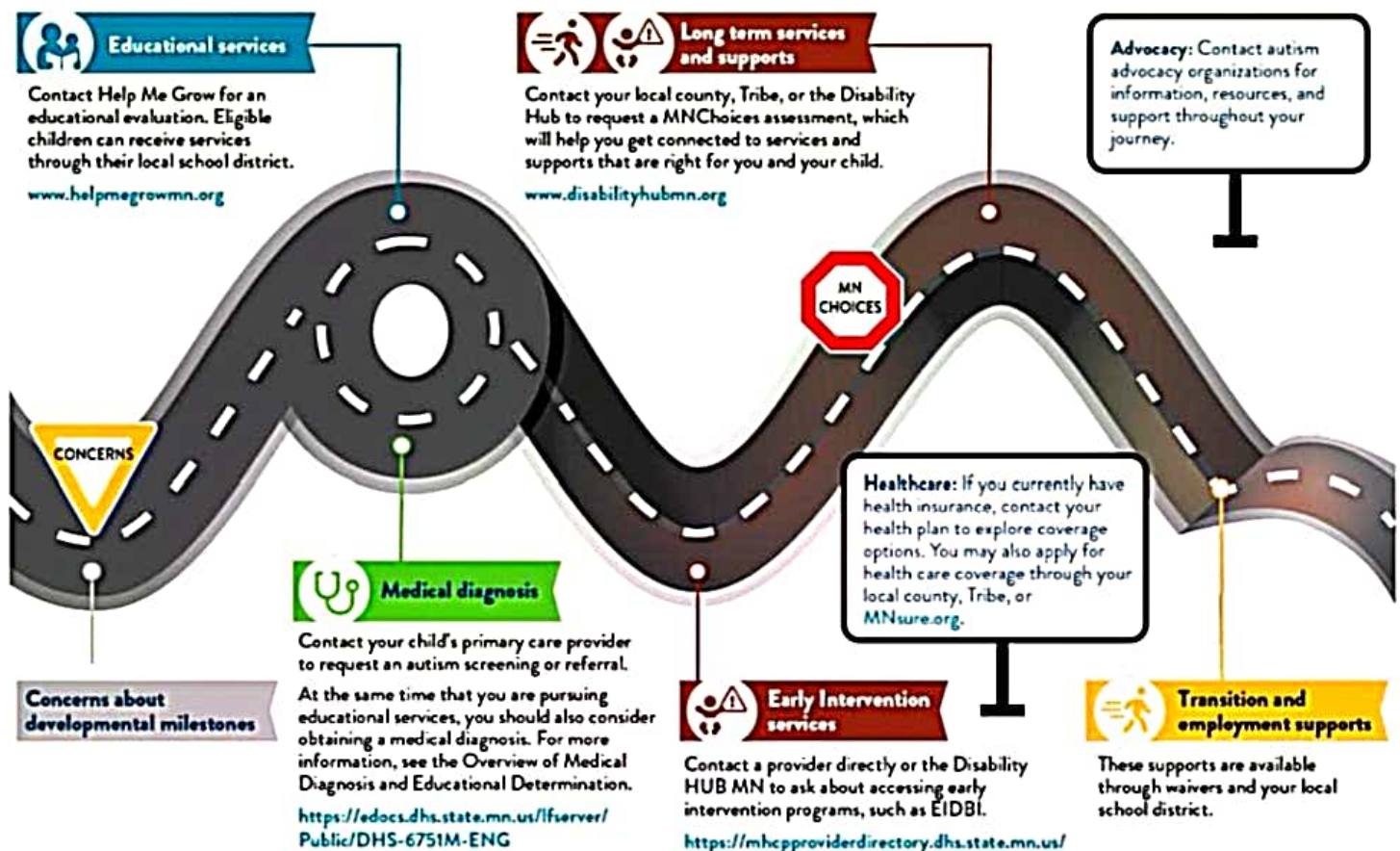## 6. EIDBI Family Interview Participation

Minnesota Region

Twin Cities Metropolitan Area

7. Journey map

Educational services

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

www.helpmegrowmn.org

Long term services and supports

Contact your local county, Tribe, or the Disability Hub to request a MNChoices assessment, which will help you get connected to services and supports that are right for you and your child.

www.disabilityhubmn.org

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

MN CHOICES

CONCERNS

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

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/

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.

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