

Early Intensive Developmental and Behavioral Intervention

A Summary of the Literature Concerning Access to and Use of Therapy

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A P R I L 2 0 2 0

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Demographic disparities in diagnosis and care

For interventions to be most effective, children with autism spectrum disorder (ASD) should be identified and served early and intensely. This involves early identification of warning signs, prompt diagnosis of ASD, and a smooth transition into receiving services and therapy, to be complemented by special education services through schools (St. Amant, Schrager, Pena-Ricardo, Williams, and Vanderbilt, 2018). However, not all children have the same access to these critical features of early and intensive care. The literature discusses the ways in which some children receive a diagnosis and treatment later and less intensively than their peers.

The Minnesota Department of Human Services contracted with Wilder Research to conduct research and evaluation related to their Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit for the treatment of people under 21 years old with autism spectrum disorder (ASD). This literature review is intended to inform DHS and other EIDBI stakeholders of identified barriers to receiving intensive interventions for autism. We have produced other reports and presented findings about the children who are receiving the EIDBI benefit and the impact of the services they are receiving as part of the ongoing EIDBI evaluation.

Differences in identification and diagnosis of autism

Overall, the United States has improved over time in diagnosing children with autism at an earlier age. This earlier identification and diagnosis of autism allows interventions to be utilized at a critical stage of development and for a longer length of time. Children with autism in the United States have not benefited from this improvement equally, however (Fountain, King, and Bearman, 2011). Disparities exist for children of color, children of families with fewer financial means, and children who are less connected or have worse access to healthcare systems, in particular. Parental awareness and perception of signs of autism can also play a role in when children are formally diagnosed with autism.

Race, ethnicity, home language, and culture

A strong evidence base shows disparities in the age at which white children and black, indigenous, and children of color (BIPOC) are diagnosed with autism spectrum disorder (Daniels and Mandell, 2014; Fountain et al., 2011; St. Amant et al., 2018). There are a variety of hypotheses as to why this difference exists, all of which are related to social and cultural factors; there is no evidence suggesting that autism prevalence varies by race (Burkett, Morris, Manning-Courtney, Anthony, and Shambley-Ebron, 2015). A systematic review of studies found that the majority of the literature highlights significant differences in age at

diagnosis between white children and children of color, and one study found that African American children specifically are diagnosed later than their peers of other races (Daniels and Mandell, 2014). African American children have been found to be misdiagnosed, and African American children with less severe symptoms are more likely to be undiagnosed than their white peers (Burkett et al., 2015). Research has identified Indigenous and Hispanic children to be the least likely to be identified as having ASD, with at some points in time half as many diagnoses as white children (Travers, Tincani, and Krezmien, 2011).

There are a variety of reasons why children of color are not being identified and diagnosed as quickly as white children, and why parents and caregivers of children of color might delay diagnosis. Implicit bias among educators, healthcare providers, and others who play a role in identifying signs and symptoms of autism is clear; African American children with autism are 5.1 times more likely to be misdiagnosed as having an adjustment disorder, and are 2.4 times more likely to be misdiagnosed as having a conduct disorder (Burkett et al., 2015).

Expectations of what appropriate and typical behavior are vary by cultural background of both children and those observing them. Parents of different backgrounds have been found to notice different potential signs of autism; parents in India noticed difficulty with socialization as a first “red flag,” whereas parents in the United States noticed developmental delays and regression in speech first (Mandell, Ittenbach, Levy, and Pinto-Martin, 2007). Different expectations of how and to what extent children socialize make an impact on what seems indicative of autism or another underlying condition to parents and others working with children.

Even when parents do identify warning signs that their child might be on the autism spectrum, they may hesitate to have their child formally diagnosed or receive treatment. Longstanding inequities in healthcare treatment for African Americans in the United States have created a sense of distrust in the healthcare system among many African American families (Burkett et al., 2015). A qualitative study of African American families who have a child with autism found that parents often believe that the best way to protect their children is to keep them from the stigma of an autism diagnosis altogether or to delay the process of receiving a medical diagnosis in order to avoid unpleasant experiences with doctors and other healthcare providers.

Language also plays a significant role in the age at which children with autism are diagnosed. Studies have found that parents’ primary language played a more substantial role in the age at which their child was diagnosed with autism than ethnicity did (St. Amant et al., 2018). Singh and Bunyak (2019) conducted a systematic analysis of qualitative studies examining disparities in autism diagnosis and treatment and found that language barriers were a consistent problem across every aspect of getting an autism spectrum disorder diagnosis, including scheduling meetings and coordinating transportation to doctors’ appointments.

This fits with other research that shows that children with immigrant mothers have later diagnoses than their peers (Fountain et al., 2011).

The most recent available data for Minnesota shows that one in 44 children have been identified to have autism spectrum disorder (MN-ADDM, 2020). Prevalence is similar for non-Hispanic white children and non-Hispanic, non-Somali black children (1 in 41 and 1 in 40, respectively). Prevalence of identified autism is lower in non-Hispanic, non-Hmong Asian or Pacific Islander children, Hispanic children, and Hmong children (1 in 60, 1 in 57, and 1 in 62 respectively). Prevalence of identified autism is higher in Somali children (1 in 34). Small sample sizes restrict the ability of the Minnesota Autism Developmental Disabilities Monitoring network (ADDM) to draw firm conclusions about differences in prevalence of identified autism for the Somali, Hmong, and Indigenous communities in Minnesota, though. Those interested in autism prevalence among different races and ethnicities in Minnesota should continue to monitor results from ADDM as experts learn more over time.

Socioeconomic status

Children of higher socioeconomic status and with more highly educated parents are diagnosed with autism earlier than their peers (Fountain et al., 2011). Research has found that socioeconomic status is a stronger predictor of the child's age at diagnosis than even the severity of their symptoms. Similar to overall trends in diagnosis, though, this wealth gap for the age of diagnosis has been shrinking over time. For those born in the early 1990s, wealthy children were diagnosed 16 months earlier than children from low socioeconomic status families; for children born in 2000, this shrank to a gap of six months between low socioeconomic status and wealthy children.

The wealth of a child's family appears to be more important than the wealth of their community. There are mixed findings on the importance of living in communities with higher median property values, lower rates of poverty, and other markers of community wealth on when a child is diagnosed with autism (Daniels and Mandell, 2014).

Geography

A 2014 systematic review found mixed results around how access to nearby medical facilities can play a role in age of autism diagnosis, but there is some evidence to show that children living in rural or otherwise non-metropolitan areas receive later diagnoses (Daniels and Mandell, 2014). Additionally, areas with more neurologists and psychiatrists, as well as areas close to a medical school, have earlier autism diagnoses (Daniels and Mandell, 2014). Future studies should examine the differences these areas have in overall diagnosis and misdiagnosis rates.

Elder, Brasher, and Alexander (2016) specifically examined barriers to early intervention for those living in rural areas. In this study, individuals working in the field and parents of children with autism discussed the general dearth of services and providers available to them in rural areas and the time and cost associated with driving to a more urban area to access services. This lack of services and providers can lead rural parents to use unproven or alternative treatments (such as the use of gluten-free and casein-free diets, vitamin supplements, or forced eye contact) with their children (Elder et al., 2016).

Existing connections to the medical community

Children who are consistently seeing a primary care doctor are more likely to receive an earlier diagnosis of autism; children who switched pediatricians in their first five years of life had later diagnoses than their peers (Daniels and Mandell, 2014). Additionally, children who were referred to specialty services and early intervention were diagnosed earlier than children who did not receive such a referral, and those who were referred from early intervention services (as opposed to receiving referrals from doctors' offices, parents, or schools) were diagnosed at an earlier age.

Simply seeing more doctors does not always result in earlier diagnosis, however. Some studies have found that seeing a greater number of physicians or other healthcare professionals is associated with a later age at diagnosis (Daniels and Mandell, 2014). It could be that seeing a higher number of healthcare professionals indicates that providers are hesitant to diagnose the child with autism or otherwise unsure of how to help parents identify the right course of action.

Parental awareness and concern

Parents are often the first to notice and follow up on their child's signs and symptoms of autism. Different levels of awareness and understanding of the signs of autism play a role in when parents bring these concerns to healthcare providers and push for their provider to make a diagnosis.

Firstborn children are diagnosed later than their peers. Some researchers have hypothesized that new parents are less aware of developmental milestones and when they should occur, so are less likely to identify "red flags" (Fountain et al., 2011).

Parental approaches to behavioral difficulties also make a difference in when children are diagnosed with autism. Parents who attribute behavioral difficulties to personality characteristics (like being difficult or being spoiled) have children who are diagnosed with autism later than parents who view behavioral issues as issues with social skills development (Daniels and Mandell, 2014).

Parents of children with autism often have other concerns about their children that compete for their attention; the majority of children with autism have at least one co-occurring condition (70%), and 4 in 10 have two or more co-occurring conditions, including both physical health issues like gastrointestinal problems and mental health issues like anxiety and depression (Fuld, 2018). Parents who were concerned about other medical issues had children who received later diagnoses than their peers (Daniels and Mandell, 2014). Researchers hypothesize that these other medical concerns “mask” the signs of autism and divert attention away from these potential autism symptoms.

Even once parents have noticed a potential sign of autism in their child, they might hesitate to bring their concerns up with their child’s healthcare provider. At other times, parents who bring up concerns might have them dismissed by a provider. Parents might delay discussing potential signs of autism with their child’s healthcare provider if they distrust healthcare systems, are discouraged by family and friends, or are told to “wait and see.” In other cases, parents might be concerned about stigma being attached to their child or family after a diagnosis, or simply not be aware of the potential benefits of speaking with a provider and getting a diagnosis is (Korbin, Celeste, Dimitropoulos, Hill, and Kampman, 2019). Even once a parent discusses their concerns with a healthcare provider, children are not always moved along a pathway of receiving a diagnosis and accessing care. Providers who are less aware of the signs and symptoms of autism or of what services are available for children and families often employ a “wait and see” approach or otherwise downplay and disregard potential signs of autism (Elder et al., 2016).

Gender

There are large differences in identified autism prevalence between boys and girls; boys are **four times** more likely to be identified as having autism than girls (Maenner et al, 2019). The literature predominately points to potential genetic and biological reasons why boys more frequently have autism than girls, as autism is a biological condition; however, the way in which autism displays itself is deeply social and cultural (Kreiser and White, 2014). Girls receive more coaching and pressure about how to behave socially than do boys; behavior changes because of this ongoing pressure might mask otherwise identifiable signs of autism in girls.

An emerging evidence base suggests that girls in the United States may be under-identified as having autism. This literature documents that girls have delayed diagnosis compared to their male peers and that girls might have to display more severe symptoms to be diagnosed with autism (Beeger, Mandell, Wijnker-Holmes, Venderbosch, Rem, Stekelenburg, and Koot, 2013; Frazier, Georgiades, Bishop, and Hardan, 2014; Kreiser and White, 2014). The vast majority of studies concerning autism and how it manifests itself use entirely or predominately male subjects. Because of that, the ways in which autism may look different in

girls and women is largely unexplored, and there could be many more girls and women with autism than the data currently reflect (Kreiser and White, 2014).

Differences in access to and utilization of care

Similar to diagnosis and identification, disparities exist in the extent to which children are accessing interventions to address their autism spectrum disorder. Underutilization is pervasive; studies have found that 9 in 10 children with ASD are not fully utilizing behavioral health services (Nguyen et al., 2016).

Race, ethnicity, and culture

Race, ethnicity, and culture play a role in how parents and caregivers perceive signs of autism in their children and how they act on concerns they have about their child's development. These factors can also impact how medical, educational, and other professionals respond to signs of autism in children and to questions and concerns from parents and caregivers, and also the way in which professionals diagnose and provide care for autism.

Singh and Bunyak (2019) conducted a meta-analysis of qualitative studies to better understand the ways in which culture affects how families respond to signs of autism in their children. In their report, they note that some cultures have a strong “wait and see” attitude, in which parents and caregivers will monitor their child over a longer period of time than parents and caregivers of other cultures before seeking professional care; they noted that this has been identified in Latinx culture, for one. Attitudes about faith can also impact whether or not a family seeks care for their child. Some parents who are first-generation immigrants to the United States said that they believed autism was a temporary condition which could be cured by faith (Singh and Bunyak, 2019).

Willingness to visit a healthcare professional is largely influenced by how one's cultural community has been historically and is currently treated by the medical community (Singh and Bunyak, 2019). African American communities, for example, have responded to pervasive disparities in quality of healthcare with distrust in the system. This can exacerbate the problem of disparities (delays in seeking care can worsen health outcomes, which furthers distrust in the system). A lack of cultural competence and the existence of bias in doctors and other healthcare providers can also contribute to distrust in the medical system among various cultural communities. Latinx and African American families of children with autism may be more likely to feel that their concerns have been dismissed by medical professionals and that medical professionals will assume their families have little education or a limited understanding of autism and other related conditions (Singh and Bunyak, 2019).

Additionally, different cultural groups perceive autism differently. Stigma associated with the diagnosis varies across different cultural and ethnic groups (Singh and Bunyak, 2019). Latinx parents have reported a need to “cover it up” when speaking about their child’s ASD diagnosis within their communities, and members of the African American community have reported that stigma around all kinds of disability is high in their community. Similar findings have come from studies with Korean and South Asian Indian communities, in which parents and caregivers feel stigmatized and shamed for their child’s autism diagnosis.

In addition to these barriers, new American families often face logistical barriers that prevent them from accessing the care their child needs. Families with undocumented status may be scared to go to a healthcare professional for fear of deportation (Singh and Bunyak, 2019). Language barriers are difficult to overcome at all steps of the process, from scheduling an appointment and discussing concerns with a doctor to filling out paperwork to access services for a child.

Studies in the U.S. have found that children of parents who primarily speak English have better outcomes than their peers. These children are more likely to access more hours of services through state-based services than children whose parents primarily speak a language other than English (St. Amant et al., 2018). Additionally, parents’ primary language being English was associated with a higher likelihood that their child’s IEP contained social skill goals and communication skill goals (St. Amant et al., 2018).

Indigenous families who live on reservation face additional barriers to accessing services. Provider shortages particularly affect rural communities, within which most reservations reside (Harley, 2018). Coupled with provider shortages are transportation issues; rural tribes are often far from providers and transportation options to get to those providers are limited, particularly for those with disabilities. General barriers for Indigenous communities living on reservations to access services include poor coordination among agencies, limited knowledge or understanding of tribal communities among providers, and financial barriers to care among individuals. Research also highlights limited enforcement of laws intended to protect individuals with disabilities and limited tribal planning to protect and support people with disabilities as barriers to service access (Harley, 2018).

Socioeconomic status

Limited access to resources for families with low socioeconomic status serves as a barrier to using services. Therapy options are often cost prohibitive unless families have access to high-quality health insurance (Singh and Bunyak, 2019). Accessing health insurance options that are available to families of children with ASD can be difficult. The process is often convoluted, which takes time and energy to understand. Parents struggling to make ends meet, especially those with a child on the autism spectrum, have little extra time and

energy to dedicate to navigating systems. Lower socioeconomic status families are more likely report that they do not have enough information about resources available to them (Singh and Bunyak, 2019). Financial barriers go beyond the cost of the therapy and care itself; for example, families without access to a car and with limited public transit options face difficulties in getting to appointments for their child's autism (Elder et al., 2016).

Geography also plays a role in the difficulty that low-income families face. Rural families have discussed financial burdens as a major barrier to accessing appropriate services for their children with ASD (Singh and Bunyak, 2019). In rural communities, therapy and healthcare providers are few and far between. The lack of resources and avenues to access evidence-based therapy is significantly associated with the use of alternative therapies and false “treatments” for autism that have no empirical evidence to support their effectiveness (Elder et al., 2016). Children of low-income, rural families are at a greater risk of not being able to benefit from therapy at the age that it matters most, and are also at risk of being put through therapeutic approaches that are at best unhelpful and can even be harmful (Elder et al., 2016; U.S. Food and Drug Administration, 2019).

Families with low socioeconomic status face particular challenges in balancing work schedules with caregiving responsibilities. This can be particularly difficult for parents of children with autism who would benefit from time-intensive therapies, such as ABA (Singh and Bunyak, 2019). Individuals on the lower end of the socioeconomic spectrum are more likely to do shift work, in which workers' hours vary widely from week to week. This makes scheduling and managing calendars difficult, especially when navigating different systems to access the range of care needed to best serve a child with autism. This challenge is particularly salient for people of color. Studies show that workers of color are significantly more likely to work on call and to have trouble getting time off (Storer, Schneider, and Harknett, 2019). The challenge of navigating childcare responsibilities and work obligations is sometimes insurmountable. Some parents will shift to working part-time or leave employment altogether because of childcare obligations (Singh and Bunyak, 2019). This disproportionately affects mothers and other female caregivers, who are expected to carry the logistical, mental, and professional burdens of caregiving to a much greater extent than their male counterparts.

Geography

As mentioned above, families living in rural areas face a unique set of challenges in accessing services. Transportation to therapy and other care can be challenging if providers are distant from the family's home. Scheduling challenges and caregiving responsibilities for other children are compounded when substantial travel to and from appointments is necessary (Elder et al., 2016). The lack of available providers within a reasonable distance can also be frustrating and demoralizing for patients. As noted above, a sense of helplessness

and insufficient access to care can lead families to turn to alternative therapies and methods of care that are ineffective and potentially harmful for children with ASD (Elder et al., 2016).

Other barriers to accessing care

There are numerous other barriers to accessing care related to family demographics, with varying amounts of literature examining these issues. Other groups that are mentioned in the literature as experiencing barriers are foster care youth, who frequently move and generally face instability in their home life, and transition-age youth, who are adjusted into adult services and systems that are difficult to navigate and understand (Singh et al., 2019).

This is not an exhaustive list of the barriers to diagnosis and care that are related to a family's demographics. Those working in the field of autism and autism services should continually think about the various hurdles different families face and work to ease burdens to access necessary care.

Approaches used to improve access to care

While it is discouraging that there are disparities in early diagnosis and access to care for children on the autism spectrum, there are concrete things that providers and others can do to help. Below are some examples from the literature about ways in which state agencies and providers can work to help children with autism from all backgrounds get their diagnosis earlier and access the services they need as soon as possible.

Policy changes

The Centers for Disease Control and Prevention (CDC) launched an effort in 2007 to promote Learn the Signs, Act Early state teams. These multidisciplinary teams aim to improve early identification and effective intervention for young children who exhibit signs of autism (Rotholz, Kinsman, Lacy, and Charles, 2019). The South Carolina Act Early Team (SCAET) was established in 2009, and its work around “presumptive eligibility” provides a promising example of ways in which states can improve early diagnosis and treatment.

The SCAET included members with decision-making authority from state agencies, advocacy organizations and foundations, universities, and health care systems, as well as families affected by autism (Rotholz et al., 2019). The action team adopted “presumptive eligibility” and developed a process by which very young children could start accessing services once they are determined to be at risk of autism, rather than waiting until they have received a formal diagnosis. This strategy has appeared to work well; after the adoption of this approach, there was a large increase in the number of children from 18 to

36 months old – the most critical time to begin services – who were eligible for and receiving Early Intensive Behavioral Interventions (EIBI). In 2010, 53 children in this age range were eligible for services, which increased to 265 children in 2015. Authors note that presumptive eligibility did not appear to provide services to children who ultimately will be determined to not have autism: only 2.5% of children who received early EIBI services through presumptive eligibility were later found to not have autism from a comprehensive evaluation.

This is one example of how policy changes can make an impact on service acquisition for children with autism. States should share their approaches, what they have learned, and measurable outcomes with one another to inform constructive and evidence-based policy change.

State agency and provider-level strategies

The literature identifies a variety of ways that state agencies and providers can work together to decrease disparities in diagnosis of and services for children who have autism.

To address disparities in diagnosis, some suggest that state agencies and providers work together to develop training materials for primary care doctors to better address parental concerns of potential signs of autism (Daniels and Mandell, 2014). Many primary care doctors will suggest a “wait and see” approach to parents, suggesting that the child will grow out of their symptoms and atypical behaviors and catch up to where they should be, developmentally. This “wait and see” approach delays diagnosis, which also delays access to support services and therapeutic interventions at the time it is most effective.

Relevant state agencies have a variety of tools they could utilize to help families in communities that have identified disparities in diagnosis age and therapy access. These include increasing case management services and conducting culturally sensitive and specific outreach to families of different races and ethnicities (Nguyen et al., 2016). The literature suggests that state agencies can work to increase overall capacity in the field by funding more treatment programs and increasing the total workforce (Elder et al., 2016).

Public awareness strategies

At a fundamental level, many people in the general public do not have an understanding of the warning signs of autism and the importance of following up on those symptoms to get a diagnosis. Many parents are scared to question their child’s development and receive a diagnosis of autism or another condition, leading them to put off raising concerns. This can be reinforced by “wait and see” instructions from pediatricians and primary care doctors when families do raise questions about signs of autism in their children.

Better information about what to look for and what to do when family members have questions or concerns about whether or not their child has autism is critical. Nguyen et al. (2016) suggests broad public education and awareness campaigns, with a specific focus on lower income households and households that are on public insurance, as they are often diagnosed later and receive fewer services for their child.

Outreach and education activities should be conducted in places where families, especially those with young children, regularly gather. These include places like cultural centers, churches, daycares, and public assistance agencies (Nguyen et al. 2016).

Wilder Research and the Minnesota Department of Human Services worked together to create the following resources, which could be used by state agencies, providers, or other stakeholders to share information with families of a child with autism:

- Autism Pathways: <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6751-ENG>
- Overview of Medical Identification and Educational Determination of Autism Spectrum Disorder: <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6751M-ENG>

The following materials could similarly be useful for these stakeholders:

- Screening fact sheet for doctors and pediatricians:
- <https://www.health.state.mn.us/docs/people/childrenyouth/ctc/devscreening.pdf>
- Autism spectrum disorder data story: <https://www.health.state.mn.us/docs/communities/titlev/autism.pdf>
- MN Learn the Signs Act Early resources: <https://addm.umn.edu/ltsae>

Issues to consider

Disparities in diagnosis and access to and utilization of care are persistent, but there are ways that agencies like Minnesota's Department of Human Services and their partners can address these issues to ensure that all children and their families have access to the services and supports they need. The following are some suggestions that are informed by the literature:

- Conduct consistent assessments of the demographics of youth in Minnesota who are accessing EIDBI benefits. Similarly, assess the amount of therapy that is recommended for each child against the amount of therapy they receive; conduct this analysis to examine differences by demographic group.
- Continue to work with partners to understand the age of diagnosis in Minnesota by demographic group.
- Continue efforts to address provider shortages, which can exacerbate differences in access to care among different demographics of children with autism.

- Increase awareness of the exception to EIDBI diagnostic rules that allows children under five with risk factors for ASD to get access to services prior to receiving a medical diagnosis. This exception can serve a similar role to presumptive eligibility, as outlined above, and could increase access to services for children in the most critical timeframe.
- Consider developing training materials and resources for primary care doctors and pediatricians so they are better able to identify signs of autism and know of next steps to take.
- Continue and expand current efforts to conduct outreach in communities that are known to experience disparities in diagnosis and care, including different cultural communities and rural areas. Outreach should be tailored to each community, use common spaces where people congregate, and be translated to different languages as needed.
- Consider increasing efforts to raise public awareness of the signs of autism and how families should move forward when they notice these signs. Public awareness campaigns should have a specific focus on communicating with groups that have demonstrated delays in diagnosis of autism.
- Consider ways to provide resources and training to medical professionals and therapy providers to better understand the ways that culture, primary language, gender, and other factors affect the ways that signs of autism may be displayed.
- Continue efforts to streamline information for parents of children with autism to ensure they are more aware of the services and benefits that might be available for them and the different courses of action they can take for their child.

Current initiatives:

With barriers to diagnosis and service in mind, the Minnesota Department of Human Services has been working with partners to make the process easier to navigate for families. These include some of the following:

- The Autism Pathways document (referenced and linked above) was assembled to provide a common document for healthcare providers and other professionals to assist families and walk through potential services and supports they could receive. This document is being translated into Hmong, Somali, and Spanish to ensure it can serve as a tool for families in communities that experience barriers to receiving services.
- The Minnesota Department of Human Services has contracted Wilder Research to conduct a Journey Mapping evaluation. Through this process, researchers systematically document families' experiences in navigating diagnosis, services, and supports they have received for their child(ren) on the autism spectrum. This project will shed light on high points and low points for families and identify ways that policies and procedures can be changed to make the process better for families. The results of this study will be publicly available in summer 2020.

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Acknowledgements

The author would like to thank Gerry Nord and Nicole Berning from the Minnesota Department of Human Services for their work to support this literature review.

The following Wilder Research staff contributed to this literature review:

Anna Alba
Amanda Eggers
Heather Loch
Nicole MartinRogers
Amanda Petersen

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