DHS-7959-ENG 8-19

# Early Intensive Developmental and Behavioral Intervention

## *A Background and Summary Overview of Minnesota's Autism Benefit Program*

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MARCH 2019

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# Executive summary

## Introduction

Wilder Research is contracted by the Minnesota Department of Human Services (DHS) to conduct research and evaluation of the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit for the treatment of people under 21 years old with autism spectrum disorder (ASD). The goals of this study are to:

1) Assess the impact of different treatment modalities on the outcomes of children with ASD or a related condition and their families, and to evaluate which of these interventions and clinical practices are the most effective

2) Understand and improve the implementation of the EIDBI evaluation, eligibility determination, and 6-month review processes (the comprehensive multi-disciplinary evaluation, or CMDE), and the development and implementation of the EIDBI Individual Treatment Plan (ITP)

To lay the groundwork for this evaluation, we completed the following activities:

- A **literature review focused on the evidence base behind the treatment modalities currently covered under Minnesota's EIDBI benefit.** As part of this review, we examined what is currently known about providing therapy to children with autism, including those children who experience co-occurring conditions or face other barriers to care, such as cultural differences and language barriers.
- A **scan of the field to better understand how other U.S. states are evaluating ASD benefit programs** in order to inform our ongoing work for this project and for future DHS ASD benefit evaluations.
- To guide this study, **we convene a Learning Collaborative (which is required as part of the EIDBI statute) comprised of ASD therapy providers, parents, policy experts, researchers who specialize in ASD, and other stakeholders.** The collaborative meets quarterly to provide ongoing feedback and recommendations to inform the EIDBI benefit evaluation in Minnesota.

This report illustrates our findings from the literature review and field scan as well as additional information provided by DHS and other sources about children who have ASD in Minnesota. We plan to produce more reports and share more results 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.

# The current state of autism in Minnesota

- ✓ Minnesota has a higher prevalence of autism than the country's average, at 1 in 42 8-year-olds vs. 1 in 59 8-year-olds nationally (Minnesota Autism Developmental Disabilities Monitoring Network, 2018).
- ✓ Diagnoses of ASD have been on the rise in recent years. Minnesota schools have identified 19,386 youth ages 0-21 as having autism, and 8,878 youth have been clinically diagnosed (Department of Human Services Medicaid Management Information System, 2018).
- ✓ Diagnoses are happening later than is ideal. The average age of diagnosis in Minnesota is nearly age 5; however, autism can be diagnosed as early as age 2 (Minnesota Autism Developmental Disabilities Monitoring Network, 2018).
- ✓ In Minnesota, boys were 4.6 times more likely than girls to be identified to have ASD than girls. This mirrors national and international trends (Minnesota Autism Developmental Disabilities Monitoring Network, 2018; National Autistic Society, 2018f).
- ✓ More than one in four (28%) Minnesota youth with ASD also had an intellectual disability (Minnesota Autism Developmental Disabilities Monitoring Network, 2018).
- ✓ Of Minnesota youth with a clinical diagnosis of ASD, 88% received some kind of services; these most commonly included mental health services, long term care services through waivers, Children's Therapeutic Services and Supports services (CTSS), and Personal Care Assistant services (Department of Human Services Medicaid Management Information System, 2018).

# Considerations when providing care

Children with autism and their families often face challenges to receiving optimal care. Providers should consider the following challenges that underserved communities face.

- ✓ Cultural differences and language barriers can keep children from being appropriately diagnosed and served. Providers and other vested stakeholders should work to break down these barriers by providing additional services in areas like translation and care coordination.
- ✓ Low-income families face a variety of barriers to getting adequate services. Even when services are covered through public insurance, these families often face issues of time and resource constraints, transportation barriers, child care issues for other children in the family, etc. These families are likely to benefit from additional outreach, care coordination, and any streamlining of services that is possible.
- ✓ The majority of children with ASD (70%) have at least one co-occurring condition, and 40% have two or more. Depression and anxiety are particularly prevalent within this population. Therapy should address a child's needs holistically, including helping the child cope with these and other co-occurring conditions.
- ✓ Additionally, children with Fetal Alcohol Syndrome (FAS) are likely to benefit from many of the same therapies as children on the autism spectrum.

# Treatments covered by Minnesota's EIDBI benefit program

For this report, we summarized available research literature about the treatment modalities that are covered by Minnesota's EIDBI benefit program. These include:

- Applied Behavior Analysis (ABA)
- Early Start Denver Model (ESDM)
- DIRFloortime® (Developmental Individualized Relationship-based)
  - PLAY Project™
- Relationship Development Intervention® (RDI)

These therapies are either behavioral approaches (ABA), developmental (DIRFloortime® and PLAY Project™), or a mixture of both approaches (Early Start Denver Model). Some key findings from the research literature about these modalities are:

- **Different outcomes have been identified for different treatment modalities.** Parents of children with autism and therapy providers should consider all available treatment modalities, which outcomes have been identified in the literature for each, and which course of action is most appropriate for the child. (More information about the outcomes of each of the EIDBI-approved treatment modalities can be found in the "Review of treatment modalities" section of this report.)
- **There are differing amounts and rigor of literature providing evidence of the outcomes associated with each treatment modality.** For a variety of reasons, including the length of time a treatment modality has been in practice, there are varying amounts of rigorous research and resulting published literature supporting the effectiveness of each modality. Parents of children with autism and therapy providers should consider the amount of evidence behind different treatment modalities when choosing a course of action for the child.
- **Therapy is best provided and reinforced in a variety of settings.** Therapy, regardless of type, has been found to be more effective when it is involved in all aspects of the child's life, from a clinical setting to school to everyday activities at home.
- **More therapy is better.** Relatedly, increasing the amount of any therapy provided has been connected to greater improvements in targeted outcomes.
- **Therapy should be provided as early as possible.** Studies have found that that earlier in life that a child starts receiving some type of therapy, the greater their gains in targeted outcomes.

# Review of other states' ASD benefit programs

We also conducted a field scan to find out more about how other U.S. states conduct evaluation of their ASD-related benefit programs and to see if there were any related best practices we should be implementing in Minnesota's EIDBI evaluation. Specifically, we explored what types of treatment modalities are covered by other states' ASD benefit programs, whether or not states conduct aggregated evaluation of their programs, progress monitoring tools and forms that other states used to evaluate their programs, and whether or not states were experiencing ASD provider shortages. We sent the survey to policy specialists from all 50 U.S. states and the District of Columbia around these topics, and 14 states responded. The following summary describes key findings from our field scan survey:

- **Most state benefits cover ABA treatment.** Ten out of 14 states indicate they cover this treatment modality as part of their ASD benefit. Most states (9 out of 14) allow for both in-home and center-based treatment under their ASD benefit.
- **Most states do not conduct evaluation of their ASD benefits.** Twelve out of 14 said they have not conducted an aggregated ASD benefit evaluation conducted by an external evaluator. Ten out of 14 states do not conduct internal evaluation around their ASD benefit programs. Four states--Iowa, Louisiana, Montana, and New Jersey -- reported that their state conducts evaluation of their ASD benefit programs.
- **Most states are experiencing ASD provider shortages.** Thirteen out of 14 states that completed our survey are experiencing provider shortages. Half of the states have provider shortages in more than one area (licensed professionals, supervisory staff, direct treatment staff, BCBAs, etc.). Four states reported shortages among direct treatment staff while two states reported shortages of licensed professionals only.

# Issues to consider

Based on the key findings outlined above, we offer the following issues to consider for DHS as we move into the next phases of the evaluation of the EIDBI benefit program.

- **Consider ongoing research and collaboration with other states to inform Minnesota's EIDBI benefit program evaluation.** There appears to be a lack of ASD benefit evaluations across states, and Minnesota is one of a few states conducting ongoing EIDBI benefit program evaluation. Starting a national learning collaborative for states to share best practices, advice, and ideas pertaining to EIDBI and ASD benefits evaluation will allow for continued strengthening of Minnesota's evaluation as well as in other interested states.
- **Consider exploring / developing a tool or process that will assess a child's progress over time in ASD treatment.** Learning Collaborative and research team members have expressed interest in exploring the development and implementation of a tool(s) or process to assess a child's progress over time that begins when they begin receiving services through the EIDBI benefit in order to determine their outcomes and the impacts on them and their families of the treatment they receive.
- **Gather more information about the experience of providing and receiving the EIDBI benefit from children, their families, service providers, and other stakeholders** to get the full picture of how the impact of the EIDBI benefit program and to identify areas for improvement.
- **Consider which treatment modalities should be covered under the EIDBI benefit and the evidence base supporting each one.** As the evaluation continues, we recommend providing more guidance and feedback with the Learning Collaborative, the EIDBI Advisory Group, and other stakeholders regarding specific treatment modalities and whether or not they should be covered under Minnesota's EIDBI benefit.

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# Introduction

The Minnesota Department of Human Services (DHS) provides an early and periodic screening, diagnostic, and treatment (EPSDT) benefit for children age 0-21 with ASD or a related condition. This program is called Early Intensive Developmental and Behavioral Intervention (EIDBI). In 2013, the Minnesota Legislature passed a law to create the EIDBI benefit for children who are up to age 18 who have ASD, and later amendments expanded eligibility to include people up to age 21 who have ASD or a related condition (Minnesota Department of Human Services [DHS], 2018a). In 2017, the Centers for Medicare and Medicaid Services (CMS) approved Minnesota's revised State Plan Amendment for the EIDBI benefit. See "Federal requirements for states to provide treatment for Autism Spectrum Disorder" page 13 for more information about the federal requirements that prompted the creation of Minnesota's EIDBI benefit.

**Defining Autism Spectrum Disorder**

The American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (commonly referred to as the DSM-5) provides common criteria to assist medical professionals in diagnosing an individual with Autism Spectrum Disorder (ASD). Broadly speaking, ASD manifests as persistent deficits in social communication and social interaction across multiple contexts, as shown through difficulty showing social-emotional reciprocity; difficulty in nonverbal communicative behaviors; and difficulty in developing, maintaining, and understanding relationships.

As the name indicates, Autism Spectrum Disorder exists along a spectrum, and each individual with autism shows symptoms in a variety of ways. It is important to note that the diagnostic criteria for autism is deficit-focused, and while this is useful in medical diagnoses, it is a limited approach to understanding people with autism more generally.

For more information on the criteria for autism spectrum disorder, please reference the American Psychological Association's information on diagnosing and managing autism spectrum disorder (https://www.apa.org/helpcenter/autism).

DHS and Wilder Research are collaborating to evaluate the EIDBI benefit in order to better understand the impact of the benefit and covered treatment modalities on children with ASD and their families. This initial information will guide DHS as it continues and improves the benefit. This report includes three sections:

1. Contextual information about autism in Minnesota and across the country, as well as contextual information about Minnesota's benefit program for its youth with ASD.
2. A literature review of the evidence base behind the treatment modalities currently covered by Minnesota's EIDBI benefit.
3. A scan of what other states across the country provide as a similar benefit.

The initial information put forth in this report will serve as an evidence-base for our evaluation of the EIDBI benefit. We plan to inform DHS, ASD therapy providers, parents/caregivers who have family members with ASD, and other stakeholders throughout the evaluation regarding our progress. We also plan to involve other states across the country in sharing best practices, challenges, and new findings so we can learn from each other and contribute to the body of research in the field.

# Minnesota's EIDBI program

Minnesota's program applies to pre-paid managed care plans that receive state funding; private insurers are not required to participate. Pre-paid managed care plans must cover EIDBI services, but they are not bound to replicate DHS's fee-for-service policies. Managed care organizations that contract with DHS must create their own policies to ensure consistent application of the benefit to children with ASD who are enrolled in their plans (DHS, 2018a). Private insurers are not required to cover EIDBI services.

## *Eligibility*

A child is eligible to receive EIDBI benefit services in Minnesota if they meet the following criteria (DHS, 2018a):

- They have been diagnosed with ASD or a related condition
- They have received a comprehensive multi-disciplinary evaluation (CMDE) that establishes medical necessity for EIDBI services
- They are enrolled in Medical Assistance (MA), MinnesotaCare, Minnesota Tax Equity and Fiscal Responsibility Act (TEFRA), or other qualifying health care programs
- They are age 0-21

A Minnesota Health Care Programs-enrolled CMDE provider determines a person meets this eligibility criteria during the CMDE process. More information on eligibility criteria can be found in the State Plan Amendment (https://mn.gov/dhs/assets/17-06-spa_tcm1053-320336.pdf).

### Funding caps and limits

Minnesota EIDBI does not have a funding cap on how much can be spent per individual or any age restrictions for those who are age 0-21. However, a child is limited to 40 hours per week of EIDBI services, so ultimately there is a limit on claims that can be paid in a year (DHS, 2018a).

## Provider and staff credentialing

In order to be eligible to provide EIDBI services under Minnesota's benefit program, a provider must meet the following conditions:

- Be enrolled as a Minnesota Health Care Program (MCHP) provider
- Meet all provider qualifications on the EIDBI assurance statement for the provider type
- Have a DHS-approved services authorization to provide EIDBI services

Currently, Minnesota has five different provider types. Each has different qualifications, roles, and responsibilities for EIDBI service delivery. They are: comprehensive multi-disciplinary evaluation (CMDE), qualified supervising professional (QSP), Level 1, Level II, and Level III providers. CMDE providers have the most experience, education, and clinical training among the providers. CMDE providers are licensed physicians, mental health professionals, or advanced practice registered nurses and are able to diagnose, evaluate, and/or provide treatment within the scope of their practice or license. On the other end of the spectrum, Level III providers have the least amount of formal training. Level III providers are employed by an EIDBI provider agency, are age 18 or older, and have any one of the following: a high school diploma or GED; fluency in a language other than English; or one year of experience as a primary personal care assistant (PCA), community health worker, waiver service provider, or special education assistant to a person with ASD or a related condition within the past five years (DHS, 2018b). Level III providers also need to complete the Level III provider training requirements during the first six months of their employment (DHS, 2018b).

Minnesota allows these variances to staff credentialing, as there is a shortage of EIDBI providers, "which may delay or prevent people's ability to access and receive EIDBI services" (DHS, 2018b). More information on the nationwide provider shortage for children who have ASD can be found under Provider shortages on page 16.

More information about Minnesota EIDBI provider qualifications, roles, and responsibilities can be found on the DHS overview of EIDBI providers (http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=DHS16_195404).

# Methods

## Literature review

For the literature review, our research librarian conducted an extensive search for literature to support the different topic areas of this report. She searched multiple journal article databases, specialized websites, and the internet for recent, research-based journal articles pertaining to the specific treatment modalities and related topics, including predicting treatment outcomes, co-occurring conditions, and barriers to obtaining treatment.

There are many differing (and sometimes controversial) beliefs and recommendations from different organizations and advocates regarding ASD and ASD interventions. We have chosen to include materials in this literature review from a variety of sources, as long as we deemed the material to be based on credible research. We excluded some articles that we did not deem to be based on credible research; these were primarily articles that did not go through a peer-review process, including some that were published by journals that were created to sell a particular therapy.

## State field scan

Wilder Research conducted an internet search to gather general information about other states' autism benefits, including the types of benefits and waivers they use, outcomes they seek and/or measure, any assessment tools in use, and state policy specialist and director contact information.

We then created a survey of other states' benefit-covered autism interventions. Respondents were identified as those listed in the National Association of State Directors of Developmental Disabilities Services list of state agencies. The survey was sent to these respondents in early October 2018. Respondents were sent two email reminders prior to the survey closing in early November 2018. Survey recipients were asked to forward the email to the person best suited to take the survey if they did not feel they could answer it fully or tell the researchers who to send the invitation to.

The survey was sent to contacts at all 50 states and the District of Columbia, for a total of 51, of which 48 were successfully delivered. Fourteen states completed the survey, for a response rate of 29 percent. Additionally, Wilder staff followed up with five states that completed the survey, asking them to clarify or provide more information for their answers. Four out of these five states provided responses to our follow-up questions.

## Learning Collaborative

For the duration of this study, we convened a group of 13 people who are ASD therapy providers, parents, policy experts, researchers who specialize in ASD, and other stakeholders to be members of a Learning Collaborative. The collaborative provides expertise and recommendations and feedback regarding the EIDBI benefit evaluation in Minnesota. The collaborative meets quarterly to provide guidance on the study.

## Limitations of this research

While reviewing the literature, we came across the following limitations. The reader should keep the following in mind:

- **There is essentially no information within autism intervention literature regarding which children benefit most from which interventions**; because of this, it is difficult to provide recommendations for specific therapeutic modalities for children with ASD who have different backgrounds or present with different symptoms and needs (Smith & Iadarola, 2015; Eapen, Crncec, & Walter, 2016).
- **More research must be done to identify "active ingredients" of treatments**. It is currently unknown which components of a given therapy lead to improved outcomes for children with ASD, as modalities encompassing a variety of strategies and activities are evaluated as a whole (Smith & Iadarola, 2015; Magiati, Tay, & Howlin, 2012).
- **There is a deficit of literature around mid-intensity therapy.** While there are many studies for low-intensity (10 hours/week) and high-intensity (40 hours/week) of therapy, there are few studies that address therapies between those two intensity levels (Harris & Delmolino, 2002).

While conducting the state scan, we encountered some additional limitations:

- **There was a low response rate to the state scan survey.** Fourteen states answered the survey, therefore these results cannot be generalized for all 50 states. More research is needed in order to get a complete picture of how states are implementing their ASD-related benefits.

Throughout this report, keep in mind that we have not yet assessed the characteristics of youth receiving EIDBI and any outcomes from the therapy they have received; this is another limitation of what we are able to present in this report.

# Children with autism in Minnesota

**Minnesota has a higher prevalence of autism than the country's average**. While 1 in 42 8-year-old children in Minnesota have been diagnosed with autism, 1 in 59 8-year-olds nationwide have been identified to have autism (Minnesota Autism Developmental Disabilities Monitoring Network, 2018).

**Diagnoses of ASD have been on the rise.** Minnesota schools have identified 19,386 youth age 3-21 to be on the autism spectrum (Minnesota Department of Education, 2018). This is substantially larger than the number that has been clinically diagnosed; 8,878 youth in Minnesota have been clinically diagnosed as having autism spectrum disorder as their primary disability category. Another 1,632 have been diagnosed with related conditions: Aspergers Syndrome, Fetal Alcohol Syndrome, Fragile X Syndrome, and Williams Syndrome (Minnesota Department of Human Services, 2018c).

While ASD can be diagnosed as early as age 2, **about half of Minnesota youth with a clinical diagnosis of autism were not given that diagnosis until close to age 5** (Minnesota Autism Developmental Disabilities Monitoring Network, 2018).

Similar to results around the country and abroad, **more boys in Minnesota have been diagnosed with autism than girls** (National Autistic Society, 2018f; Minnesota Autism Developmental Disabilities Monitoring Network, 2018). The Minnesota Autism Developmental Disabilities Monitoring Network found in an analysis of 2014 data that while there appeared to be a higher prevalence among Somali and Hmong children in Minnesota, sample sizes were too small to confirm this is a statistically significant difference (2018). **Over one-quarter (28%) of Minnesota youth with ASD had an intellectual disability** (Minnesota Autism Developmental Disabilities Monitoring Network, 2018).

**Of the Minnesota youth that were clinically diagnosed with ASD, 88 percent received services.** The most common services provided were mental health services, which includes services like day and residential treatment, behavioral health home services, and diagnostic assessments; long term care services through waivers; Children's Therapeutic Services and Supports services (CTSS); and Personal Care Assistant services (Minnesota Department of Human Services, 2018c) (see https://mn.gov/dhs/people-we-serve/children-and-families/health-care/mental-health/programs-services/).

# Co-occurring conditions

Some children with ASD have other co-occurring conditions that should be considered when determining therapy courses for children receiving services. For this review, we have specifically focused on trauma, anxiety, depression, and Fetal Alcohol Syndrome as co-occurring conditions, per DHS's request. These are just a few of the many co-occurring conditions that can affect children and adults with autism. In fact, **the majority of children with ASD (70%) have at least one co-occurring condition, and 40 percent have two or more** (Fuld, 2018).

## Trauma, anxiety, and depression

Autism and detrimental mental health oftentimes go hand in hand. Autism diagnosis has been found to be significantly associated with reports of trauma; those with autism are more likely to report adverse childhood experiences (ACEs), and reports of PTSD and trauma are particularly elevated for women with severe autistic traits (Fuld, 2018).

Children with ASD are particularly vulnerable to traumatic experiences because of the difficulty they face in reading social situations and emotional regulation. They frequently experience the day-to-day trauma of bullying and social isolation, and tend to lack the peer support networks that can buffer the effects of bullying (Hoover, 2015).

In addition, suicidal ideation has been found to occur 28 times more frequently for those on the autism spectrum than their neurotypical[1] peers (Fuld, 2018).

Some recommendations for improving therapeutic experiences for children who have or still experience trauma, anxiety, and depression include:

- Ask children and adolescents to self-report any previous trauma in addition to asking parents or guardians; self-reports may be more complete (for example, including accounts of bullying at school that is unknown to parents; Hoover, 2015).
- Be flexible in the use of assessment tools, as there is a current dearth of tools for this specific population. This can include:
  - Using symptom measures designed for neurotypical children and adolescents, but with caution (Hoover, 2015).
  - Using assessment scales that are currently in use in research studies on ASD and trauma (Fuld, 2018).

[1] Neurotypical is a term that refers to a person who does not display symptoms of autism or other neurological atypical patterns of thought or behavior.

- Work with this population within therapy to, in addition to addressing symptoms of ASD, help them regain a sense of power, a sense of connection with others, and senses of emotional and physical safety (Harvey, 2012).

These practices should be considered as a complement to standard therapeutic practices within each of the treatment modalities outlined in this report. Further research is needed to determine whether or not specific treatment modalities outlined in this report would be particularly useful for autistic children with trauma, anxiety, and depression.

## Fetal Alcohol Syndrome

Researchers have found that nearly 3 percent of children with fetal alcohol syndrome (FAS) have also been diagnosed with autism spectrum disorder (Lange, Rehm, Anagnostou, & Popova, 2017). Similar to autism interventions, parents and caregivers of children with FAS are encouraged to enroll their child in developmental therapies at an early age to receive the most benefit (Centers for Disease Control and Prevention, 2018). Additionally, the creators of the Developmental, Individual-Difference, Relationship-Based (DIR™) model, which is the model upon which DIR/Floortime™ (as discussed below) is based upon, suggest that this model could be effective for children with FAS (Greenspan & Wieder, 1998). Further research is needed to determine whether or not the treatment modalities outlined in this report would be useful for children who have co-occurring fetal alcohol syndrome and autism.

## Barriers to service

Many families encounter barriers to service or challenges in receiving the amount of services that is ideal to their child with ASD. These can include financial and time constraints, as well as challenges like language barriers, access to transportation, child care needs for other children in the family, and geographic distance between patient and provider.

Low income can serve as a serious impediment to both identification of and service for children with ASD. Children of lower-income families have been found to receive diagnosis of ASD later than their peers from higher income families (Khowaja, Hazzard, & Robins, 2015). Children with mothers with lower educational attainment levels were more frequently found to be misdiagnosed in initial screening, which Khowaja et al. (2015) hypothesize is related to lower levels of knowledge about expected developmental steps for their child and literacy issues.

Communication with lower-income families can be difficult, as these families are more likely to miss communication because they are balancing multiple jobs, have short-term phone plans, etc.; these communication issues can serve as an impediment to continuing with additional screening or with receiving care. Lower-income families are also less likely to come to a scheduled appointment; this could be due to other life stressors getting in the way (Khowaja et al., 2015).

Some recommendations for working to reduce logistical and financial constraints include:

- Hire care coordinators to administer screening, make referrals, and develop an action plan for care; this has been found to be helpful for low-income families (Roux et al., 2012).
- Conduct outreach in socioeconomically disadvantaged communities to improve parental identification of ASD symptoms (Khowaja et al., 2015).
- Provide an option for parents, especially those who are English language learners, to request that forms and other documents be read aloud to them (Khowaja et al., 2015).
- Streamline processes for families, especially those overwhelmed with other life stressors (Khowaja et al., 2015).
- Consider ways to subsidize transportation costs or assist families in getting to therapy (Khowaja et al., 2015).

# Cultural differences

### *English Language Learners and identification of children from various racial/ethnic backgrounds with autism*

There are racial and ethnic differences in who is screened for and identified as having autism. Mild symptoms of autism, for example, might be confused with cultural differences by a family doctor or school-based professional, leading to delayed screening or a complete lack of screening (Dyches, 2011). These barriers have been shown to lead children of racial and ethnic minority groups to receive diagnoses at older ages and with more severe symptoms.

Zuckerman, et al. (2014) explored the reasons why Latinx children receive diagnoses later on and for more severe cases. In this case, low levels of knowledge about autism and its symptoms, as well as stigma around mental health and disability in the Latinx community, were found to compound with poor access to care due to low socioeconomic status and language barriers. Therapy providers, as well as school-based professionals, pediatricians, and other professions working with young children should be conscious of these cultural differences in identifying children to be screened and take additional steps to ensure that children of all backgrounds, be they cultural, financial, or otherwise, be given the same chance at participating in helpful therapy.

Below are some recommendations for those working to identify children to be screened and assessing children for ASD. They include short-term goals that are immediately actionable and long-term suggestions for the field to work toward in the coming years.

- Interviews and other interactions with the child for the purpose of diagnosis should be conducted in a child's native language (Dyches, 2011).
- Use a translator whenever possible to minimize the impact of language differences, including communicating with parents or caregivers in their native language (Dyches, 2011).
- Use strengths-based approaches to screening and determining interventions for ASD; these approaches can better build on a family's racial, ethnic, and socioeconomic background as a resource for improved outcomes for children with ASD (Tincani, Travers, & Boutot, 2009).
- Be aware of cultural differences (including different approaches to eye contact, sarcasm, and physical touch) and consider these when determining whether or not to diagnose a child with ASD (Dyches, 2011).

- Evaluate parents' perceptions and awareness of the child's ASD, including questions around parents': knowledge and awareness of the clinical features of ASD (e.g., "How does autism affect your child") and short- and long-term goals for intervention (Tincani et al., 2009):
  - Involve families in the intervention process to allow for better contextual fit within the family's norms and culture (Tincani et al., 2009), including:
    - Identification of behaviors to focus on in therapy.
    - Development of interventions for the family to use at home or in community settings.
- Conduct outreach in a variety of communities that might be less aware of state resources or have historically utilized these resources less, including immigrant, refugee, and low-income communities. DHS and other stakeholders should also work to increase awareness of symptoms of ASD and what resources are available to families (Zuckerman, et al., 2014).
- Work broadly to de-stigmatize autism spectrum disorder, particularly in communities with particularly high levels of stigma (Zuckerman, et al., 2014).
- Recruit a diverse workforce to allow members of a community to work with someone knowledgeable of their culture (Dyches, 2011).
- Use culturally specific tools whenever possible and adapt tests to work within differing cultural contexts (Dyches, 2011).

# A review of the treatments Covered by Minnesota's Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit program

As autism spectrum disorder (ASD) rates have increased among children, so have efforts to better understand the disorder and the ways in which service providers and parents can help reduce the detrimental aspects of the condition. With the wide variety of (sometimes inaccurate) information about the causes of autism and ways to address it, many families who have a child with ASD feel as if they are without real answers to the questions they have.

While the research base around ASD and the range of therapies to address it is relatively new, there are some treatment modalities that have a consistent evidence base; that is, those with rigorous research and evaluation (e.g., numerous randomized controlled trials and within-subject experimental analyses) that demonstrate their impacts. Beyond these, there are a variety of therapeutic models that have less evidence to back them, and some that have very little or no evidence - some may even show harmful impacts on children.

Families pursuing therapy for their child with ASD should, to the degree they can, be aware of the current evidence base and choose therapeutic modalities for their child with this evidence (and the advice of professionals who they trust) in mind. Providers should regularly review literature around the effectiveness of various therapeutic modalities for ASD to inform their use of treatments and interventions for their patients. The Minnesota Department of Human Services and other state and federal government agencies that provide ASD benefits should be aware of this research when determining which treatment modalities to include in their programs.

The goal of this review is to examine the evidence surrounding treatment modalities currently covered by Minnesota's EIDBI benefit. We aim to identify how therapy providers and caregivers can support children with ASD and their families to address the problematic aspects and symptoms of ASD that impair quality of life or limit the child's full potential. Early intensive treatments are intended to improve a child's functional skills and address any problem behaviors, but are not intended to "cure" the ASD, which may also be an important aspect of individual differences.

We compiled the following summaries from the research literature about each treatment modality available through Minnesota's EIDBI benefit program. These are:

- Applied Behavior Analysis (ABA)
- Early Start Denver Model (ESDM)
- DIRFloortime® (Developmental Individualized Relationship-based)
  - PLAY Project™
- Relationship Development Intervention® (RDI)

The following summaries reflect the state of literature at the time of publication; the research literature will continue to evolve and provide more nuanced understanding of what works and for whom in the field of autism intervention for children.

Some websites that provide helpful, unbiased, and research-based information about ASD and ASD treatment options and resources can be found in the Appendix.

**Important note.** Some ASD therapies are trademarked enterprises, and those who financially benefit from the use of these therapies may advertise them broadly. In other words, a very well-known therapy with a lot of "brand name" recognition is not necessarily an evidence-based therapy.

It is crucial for parents, caregivers, providers, and government agencies that fund ASD treatment to be vigilant and to have access to clear and accurate information about the quality of the research behind various treatment modalities as they advocate for their children/patients /consumers.

**A note about our methods.** There are many differing (and sometimes controversial) beliefs and recommendations from different organizations and advocates regarding ASD and ASD interventions. We have chosen to include materials in this literature review from a variety of sources, as long as we deemed the material to be based on credible research. We excluded some articles that we did not deem to be based on credible research; these were primarily articles that did not go through a peer-review process, including some that were published by journals that were created to sell a particular therapy.

### *General challenges and limitations*

Across all of the following summaries, keep in mind the following:

- There is essentially no information within autism intervention literature regarding which children benefit most from which interventions; because of this, it is difficult to provide recommendations for specific therapeutic modalities for children with ASD who have different backgrounds or present with different symptoms and needs (Smith & Iadarola, 2015; Eapen, Crncec, & Walter, 2016).
- More research must be done to identify "active ingredients" of treatments. In other words it is currently unknown which components of a given therapy lead to improved outcomes for children with ASD, as modalities encompassing a variety of strategies and activities are evaluated as a whole (Smith & Iadarola, 2015; Magiati, Tay, & Howlin, 2012).
- There is a deficit of literature around mid-intensity therapy. While there are many studies for low-intensity (10 hours/week) and high-intensity (40 hours/week) of therapy, there are few studies that address therapies between those two intensity levels (Harris & Delmolino, 2002).

## Applied Behavior Analysis

Applied Behavior Analysis (ABA) is a therapeutic method in which an individual's behavior is systematically analyzed, areas for behavioral change are identified by a therapist, and then the therapist uses appropriate methods to guide targeted behavior changes. This can include the therapist modeling desired behavior and rewarding the child when that behavior is shown (National Autistic Society, 2018a). This method was developed by Dr. Ivar Lovaas, which was brought to the field as evidence-based in 1987 with the publication of his article "Behavioral Treatment and Normal Intellectual Functioning in Young Children with Autism," (Smith & Iadarola, 2015; The Lovaas Center, 2018).

ABA can be utilized in clinical settings with a therapist, and parents may supplement this with additional therapy at home. Sometimes parents take over primary therapy responsibilities after being trained by the child's therapist. Parental facilitation of ABA should be monitored by a therapist through observation and supervision or check-ins between caregiver and therapist.

ABA is a behavioral intervention, which means it targets specific, outward behaviors to reinforce "good" behaviors and discourage "bad" behaviors. This is based on the guiding idea that behavior can be changed by adjusting what happens immediately before and/or after that behavior occurs. This differs from developmental interventions, which target specific developmental areas of focus in an individual rather than their outward behaviors (National Autistic Society, 2018a). Some treatment modalities utilize both behavioral and developmental components (including the Early Start Denver Model, which is described later in this report).

ABA is a broad umbrella that covers a variety of specialized treatment interventions, including discrete trial training and pivotal response training. It is a flexible approach that allows the therapist to make adjustments to the approach after assessing the child and how they react to the therapy (National Autistic Society, 2018a).

This method is commonly used for children and adults with ASD, as well as individuals with other conditions and developmental delays (National Autistic Society, 2018a). Overall, ABA has been recognized as effective and evidence-based (Welch & Polatajko, 2016; Matson, et al., 2012).

Information about ABA certification and resources can be found at:

**Association of Behavior Analysis International (ABAI)**
**https://www.abainternational.org/welcome.aspx**

**Behavior Analyst Certification Board (BACB) https://www.bacb.com/**

### *Clinical findings and outcomes*

Studies have identified the following benefits of ABA therapy for children with ASD.

- **Increased IQ scores/intellectual functioning/academic skills** (Roane, Fisher, & Carr, 2016; Virues-Ortega, 2010; Linstead, et al., 2017; Peters-Scheffer, Didden, Mulders, & Korzilius, 2013; Roth, Gillis, & Reed, 2013; Smith & Iadarola, 2015)
- **Improved peer engagement and social functioning/behavior** (Welch & Polatajko, 2016; Virues-Ortega, 2010; Linstead et al., 2017; Peters-Scheffer, et al., 2013; Leaf et al., 2016; Roth, Gillis, & Reed, 2013; Vismara & Rogers, 2010)
- **Improved communication skills, including increased mean length of utterance, language development, nonverbal communication, and receptive language** (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014; Virues-Ortega, 2010; Linstead et al., 2017; Peters-Scheffer et al., 2013; Vismara & Rogers, 2010)
- **Improved adaptive behavior** (Virues-Ortega, 2010; Peters-Scheffer et al., 2013; Roth et al., 2013; Smith & Iadarola, 2015; Welch & Polatajko, 2016; Linstead et al., 2017)
- **Increased support of play and leisure activities** (Welch & Polatajko, 2016; Peters-Scheffer et al., 2013; Vismara & Rogers, 2010; National Autism Center, 2015)
- **Minimized disruptive/problem behaviors** (Welch & Polatajko, 2016; Roth et al., 2013; National Autism Center, 2015)
- **Developmental age,** the age equivalent of where a child functions emotionally, physically, cognitively, and socially (Peters-Scheffer et al., 2013)
- **Phobic avoidance** (Roth et al., 2013)
- **Non-verbal IQ** (Linstead et al., 2017)
- **An increased amount of unprompted responses** (Matson, et al., 2012)
- **Improved self-management**, which includes self-monitoring, self-observation, self-evaluation, self-recording, and self-reinforcement (Carr, Moore, & Anderson, 2014)
- **Increased joint attention**, in which the child and their therapist or caregiver both hold focus on a common object (Vismara & Rogers, 2010)
- **Increased imitative behavior**, in which the child imitates a caregiver or therapist's behavior (Vismara & Rogers, 2010)
- **Improved parent-child engagement** (Vismara & Rogers, 2010)
- **Reduced autism symptom severity** (National Autism Center, 2015)
- **Improved motor skills** (National Autism Center, 2015)

Regarding the anticipated magnitude of outcomes for patients, studies have found that long-term, intensive ABA produced large, positive effects on language-related outcomes (Linstead et al., 2017) and IQ (Smith & Iadarola, 2015), as well as moderate, positive effects on non-verbal IQ, social functioning, daily living skills (Linstead et al., 2017), and adaptive behavior (Smith & Iadarola, 2015).

Studies have noted that between 30 and 47 percent of children in Early Intensive Behavioral Intervention (EIBI) make reliable gains in cognitive and educational functioning (Smith & Iadarola 2015; Zachor & Itzchak 2010, respectively) and about 20 percent make reliable gains in adaptive behavior (Smith & Iadarola 2015). EIBI only utilizes behavioral interventions (ABA), while Minnesota's EIDBI program adds to this by also providing support for developmental interventions.

### *Recommendations for use*

Outcomes for IQ, nonverbal IQ, and adaptive behavior were slightly better for clinic-based programs, as opposed to parent-managed programs (Virues-Ortega, 2010); however, parent-managed programs are increasingly noted as having similar outcomes for children as clinic-managed programs (Matson, et al., 2012).

Zachor and Itzchak (2010) stress the importance of parental involvement in all types of treatment interventions for children with ASD (i.e., ABA and all other treatment modalities described in this report); outcomes for children can be expected to be greater when treatment provided by a therapist is affirmed and consistently provided at home and in other settings.

Overall, studies have found that outcomes are better with high-intensity as opposed to low-intensity therapy[2] for children who begin therapy earlier, and for children who are higher functioning upon entry to therapy when compared with those who are lower functioning (Peters-Scheffer et al., 2013). However, one notable study found that children across a wide range of ages benefited similarly from intensive ABA (Linstead et al., 2017).

Some studies have examined the role of treatment intensity and duration on different types of outcomes. This research found that some outcomes -- namely, gross and fine motor skills and daily living skills – are slow to change regardless of treatment intensity (Linstead et al., 2017). However, language, cognitive, and academic skills are quite responsive to both treatment intensity and duration (Virues-Ortega, 2010).

[2] Low-intensity treatment is generally given a benchmark of around 10 hours a week, and high-intensity treatment is generally benchmarked at 30-40 hours of intervention a week.

Clinicians should consider this when determining how much time to spend on targeting different types of therapy. Therapists should spend fewer hours per week over a longer period of time on outcomes that are only weakly responsive to therapy (motor skills, daily living skills, and executive function skills, which include mental control and self-regulation; Linstead et al., 2017) and focus more intensively on outcomes that are highly responsive to therapy (language, cognitive, and academic skills; Virues-Ortega, 2010).

Under the ABA umbrella, there are many focused therapies that hone in on a particular skill they would like the child to advance in. Focused therapy is smaller in scope (at fewer than 50 hours of therapy), but has been found to have positive impacts on establishing and expanding social communication, a common area for focused therapy (Smith & Iadarola, 2015).

One study assessed the impact of supervision hours, supervisor credentials, years of experience, and caseload on the number of outcomes children with ASD mastered through therapy. They found that supervisor credentials (whether or not a supervisor has Behavior Analyst Certification Board certifications) and years of experience of a clinical supervisor had a significant impact on the number of mastered learning objectives for children with ASD. The authors found that for each additional year of experience of a supervisor, patients saw a 4 percent increase in mastered learning objectives. They found that increased supervision hours and caseload size were not significant predictors of the number of mastered learning objectives of the patients seen by these clinicians (Dixon, et al., 2016). Because of this, the authors suggest that the 2012 version of the BACB guidelines be followed, which suggests 1-2 hours of supervision for every 10 hours of treatment. (The 2014 version of these guidelines suggests a greater amount of supervisory hours; Dixon et al., 2016.) Funding-wise, resources should be redirected away from excessive supervision and toward hours spent providing therapy to clients (Dixon et al., 2016).

ABA therapy has generally been found to produce better cognitive, language, and daily living skills outcomes for participants than developmental therapy models (Zachor & Itzchak, 2010).

Zachor and Itzchak (2010) compared groups of children receiving ABA therapy and eclectic therapy (in this case, DIRFloortime® and TEACCH were combined for the eclectic therapy group). These groups did not show significant differences in outcomes; the authors note that this emphasizes the importance of early diagnosis and intervention;

they concluded that the specific type of intervention might not be a major factor in child outcomes.[3]

## *Challenges and limitations*

**Evidence is largely limited to within-subject analysis on short-term outcomes.**

ABA might be deemed to only have a low-to-moderate evidence base if we only consider randomized controlled trials (in which subjects are randomly sorted into treatment and control groups, which allows researchers to identify the treatment as the cause of patient outcomes) as sufficient evidence. However, if we were to also consider studies that include within-subject experimental analyses (in which all participants undergo treatment, and analysis is done on outcomes from pre- to post-treatment), ABA is more likely to be deemed as having a strong evidence base (Roane et al., 2016).

There is limited information about long-term effects of ABA; most studies that include a follow-up assessment after treatment (as opposed to only including immediate end-of-treatment results) tend to have short follow-up periods (a few months as opposed to a few years or beyond) (Estes, et al., 2015; Magiati et al., 2012).

**Because ABA is a flexible modality, it is difficult to examine similar experiences across patients.**

Because ABA is a broad umbrella, studies concerning the impacts of ABA consist of a heterogeneous mix of individuals receiving therapy, including their age, the severity of symptoms they experience, and the specifics of therapy delivery (Magiati et al., 2012).

There is also a need for greater research into fidelity of use of ABA interventions, as well as the alternative types of interventions against which ABA is compared (Harris & Delmolino, 2002; Magiati et al., 2012).

[3] It should be noted that this study did not randomize ABA vs. eclectic therapy groups; the therapy they were assigned was determined by home address.

# Early Start Denver Model

The Early Start Denver Model (ESDM) is a play-based comprehensive early intervention for children with ASD who are very young (age 12-48 months) that integrates developmental, ABA, and relationship-based approaches. It is comprehensive in that it attempts to address all needs of a child, rather than specific goals (Magiati et al., 2012). ESDM focuses on imitation, nonverbal communication (like joint attention), verbal communication, social development, emotion sharing, and play (Roane et al., 2016). This therapy was developed by Drs. Sally Rogers and Geraldine Dawson, who now practice at the UC Davis MIND Institute, which facilitates ESDM training. Dr. Rogers and her colleagues at the University of Colorado Health Sciences Center began development of the model in 1981 (Davlantis & Rogers, 2016; National Autistic Society, 2018c).

In this intervention, therapists or caregivers aim to improve a child's social and communication skills and interaction. They do this through shared attention on common objects and activities, which oftentimes comes from parents or therapists noticing what interests a child and joining in to that interest, and progressively building on verbal and nonverbal communication skills (Dawson et al., 2009). Rogers et al. (2017) notes that treatment should be embedded within everyday activities for children with ASD, both within their families and with their peers (with adult supervision and teaching).

ESDM therapists may be psychologists, behaviorists, occupational therapists, speech and language pathologists, early intervention specialists, or developmental pediatricians; these professionals must attend a training workshop and submit videotapes of themselves providing ESDM therapy, which is assessed by staff at the University of California, Davis to become certified.

For additional information about becoming certified and access to curriculum, visit:

**UC Davis Extension:** https://extension.ucdavis.edu/subject-areas/early-start-denver-model

### *Clinical findings and outcomes*

Studies have identified the following benefits of ESDM therapy for children with autism spectrum disorder.

- **Increased IQ and cognitive/intellectual ability** (Dawson, Jones, Merkle, Venema, Lowry, Faja, Kamara, Murias, Greenson, Winter, Smith, Rogers, & Webb, 2012; Estes, et al., 2014; Eapen et al., 2013; Dawson et al., 2012; Rogers et al., 2017; Eapen et al., 2016)
- **Reductions in symptom severity (namely, social and communicative impairments and repetitive or restricted interests and behaviors)** (Estes et al., 2015; Vismara & Rogers, 2008; Dawson et al., 2012; Rogers et al., 2017; Eapen et al., 2016)
- **General language improvements, as well as improvements in receptive and expressive language** (Dawson, et al., 2009; Vivanti, et al., 2014; Fulton, et al., 2014; Rogers et al., 2017; Eapen, et al., 2013; Eapen et al., 2016; Dawson et al., 2012)
- **Improvements in daily living skills** (Dawson et al., 2010; Estes et al., 2015; Dawson et al., 2012; Rogers et al., 2017)
- **Increased imitative behaviors**, in which the child copies a caregiver or therapist's behavior (Rogers, et al., 2012; Vismara & Rogers, 2008; Eapen et al., 2016)
- **Increased spontaneous language** (expressive language, verbal or nonverbal, that happens in the absence of prompts, instructions, or other verbal cues) (Rogers et al., 2012; Vismara & Rogers, 2008; Eapen et al., 2016)
- **Reduced problem behavior**, such as self-harm and violence (Fulton et al., 2014; Estes et al., 2015; Rogers, et al., 2017)
- **Improved visual reception** (the ability to understand the meaning of symbols, pictures, and other concrete objects) (Fulton et al., 2014; Eapen et al., 2013; Eapen et al., 2016)
- **Improved cooperative social behavior** (positive engagement with peers), which supports the development of social-cognitive and social emotional skills like empathy (Rogers et al., 2017)
- **Increased age-appropriate toy play** (Rogers et al., 2017)
- **Increased attention to faces** (Smith & Iadarola, 2015; Rogers et al., 2012), which leads to greater understanding of human facial expressions and the insight they provide, including the emotional state of others and their level of engagement in conversation (Leopold & Rhodes, 2010), both of which are important in communication with others

Estes et al. (2015) conducted an analysis two years after ESDM therapy ended (participants were age 2 when they began therapy, age 4 when they ended therapy, and received follow-up assessment at age 6). They found that children maintained gains made in intellectual ability, adaptive behavior, symptom severity, and challenging behavior; this indicates that there was not regression after therapy ended. Additionally, this study found that while those who received ESDM therapy did not differ from the comparison group in core autism symptom severity and adaptive behavior at the end of therapy, at the two-year follow-up, the ESDM group did show significant improvements in these realms.

### Recommendations for use

Treatment and assessment plans should be developed with interdisciplinary input from experts in a variety of fields, including, but not limited to, communication, motor development, early cognitive development, early childhood education, and behavior analysis (Rogers et al., 2017).

Comprehensive assessment of a child's current abilities should guide the development of an individualized plan for supporting social development (Rogers et al., 2017). (Although this recommendation was in the context of a study about ESDM, we believe it is applicable to all of the ASD treatment modalities allowed by Minnesota's EIDBI benefit.)

### Challenges and limitations

We did not identify any challenges or limitations of the Early Start Denver Model in the research literature.

# DIRFloortime® and PLAY Project™

## Overview

DIRFloortime® (Developmental, Individual Difference, Relationship-Based Model) uses play as a means by which adult caregivers can guide children with ASD to meet developmental milestones; this is a developmental intervention. In this modality, parents and caregivers get down on the floor and play with their child. They are instructed to follow the lead of their child by focusing on what their child is interested in. With that attention, the parent/caregiver should then direct the child through exercises that address increasingly complex goals (National Autistic Society, 2018b). Dr. Stanley Greenspan developed this therapeutic model around the 1990s (Greenspan Floortime, 2018).

Within this treatment modality falls the PLAY Project™ Home Consultation program, which is based on the DIRFloortime® method (Solomon et al., 2014).

For information about certification in DIRFloortime® and the curriculum, visit:

**The Interdisciplinary Council on Development and Learning:**
http://www.icdl.com/home

## Clinical findings and outcomes

Research studies have identified the following benefits of DIRFloortime® therapy and PLAY Project™ therapy for children with ASD. It should be noted that research into the effectiveness of DIRFloortime® is limited (Mercer, 2017; please see "Challenges and Limitations."

- **Improved logical and creative thinking** (Hess, 2013)
- **Increased shared attention** (Hess, 2013; Solomon et al., 2014)
- **Improved relationships** (Hess, 2013)
- **Increased social engagement** (Mahoney & Solomon, 2016)
- **Increased spontaneous communication** (Hess, 2013; Solomon et al., 2014)
- **Improved communication (general)** (Liao et al., 2014; Oono, Honey, & McConachie, 2013)
- **Improved adaptation to the feelings of others** (Hess, 2013)
- **Improved emotional functioning and development** (Liao et al., 2014; Solomon et al., 2014)

- **Improved daily living skills** (Liao et al., 2014)
- **General improvement in the Functional Emotional Assessment Scale** (Pajareya & Nopmaneejumruslers, 2011)
- **Reduced autism symptom severity** (Oono et al., 2013)

### *Recommendations for use*

Zachor and Itzchak (2010) compared groups of children receiving ABA therapy and eclectic therapy (a combination of different developmental therapy models, in this case, DIRFloortime® and TEACCH). These groups did not show overall differences in outcomes, but did show some variability in response based on severity of autism symptoms. Those with less severe autism symptoms who received eclectic intervention had better outcomes. Therefore, the authors emphasize the importance of early intervention for children with ASD, but note that the specific type of intervention might vary based on the child's baseline social abilities and deficits.

### *Challenges and limitations*

**Current evidence is insufficient in demonstrating effectiveness.**

A 2017 meta-analysis conducted on research about DIRFloortime® therapy came to the conclusion that, based on the research available to them, it cannot be concluded that this is an effective treatment for ASD. Many studies that are used as evidence of effectiveness for this treatment modality were deemed to have weak design; therefore, there is not good support for the effectiveness of this therapy modality (Mercer, 2017).

The National Autistic Society (National Autistic Society, 2018b) notes that while there is some very limited research to suggest that this modality may improve the quality of interactions between some children with ASD and their parents, there is insufficient research to provide evidence of any other benefits that come to children who receive DIRFloortime®.

The National Autism Center (2015) classifies DIRFloortime® as an "unestablished intervention." They state that there is little to no evidence in the scientific literature to draw firm conclusions from, and that there is no reason to assume the intervention is effective. Further, they say that there is no way to rule out the possibility that it is ineffective or harmful.

The State of California passed legislation in 2009 that mandated that autism treatment provided at state-funded regional centers must be evidence-based. DIRFloortime® was

determined to not have sufficient evidence, and has thus been pulled as an option for California families receiving autism services at these regional centers (Griffin, 2010).

# Relationship Development Intervention® (RDI)

## *Overview*

Relationship Development Intervention® (RDI) is a family-based approach to autism that aims to build "dynamic intelligence" for children with ASD. The approach aims to improve "core issues" of autism, including motivation, communication, emotional regulation, episodic memory, rapid attention-shifting, self-awareness, executive functioning, flexible thinking, and creative problem solving (RDIconnect™, 2018). It was developed in the 1980s by clinical psychologists Steven Gutstein and Rachelle Sheely (National Autistic Society, 2018e). Consultants trained through this program coach parents in identifying objectives for their child and family and integrating steps into their daily routines to accomplish these objectives. Some examples of these objectives include "simplifying the home environment, slowing down the pace of life, and balancing the entire family's schedule" (RDIconnect™, 2018).

For additional information about RDI, including resources around utilizing RDI and becoming an RDI consultant, visit:

**RDIconnect™:** https://www.rdiconnect.com/about-rdi/

## *Challenges and limitations*

**Current evidence is insufficient in demonstrating effectiveness.**

There is insufficient evidence for the effectiveness of this therapy modality. There is one study that assesses the impacts of RDI on children with ASD (Gutstein, Burgess, & Montfort, 2007); that article has been deemed by the field to be of very limited scientific validity and reliability (National Autistic Society, 2018e; Zane, Davis, & Rosswurm, 2008).

# Review of other states' ASD benefit programs

Wilder Research completed a field scan by sending a survey to all 50 states and DC to learn more about how other states design, implement, and evaluate the effectiveness of their benefits, waivers, and treatment programs for children with ASD and related conditions, including how they measure progress for individual children who receive services and/or for the program overall. Additionally, we wanted to know more about what types of client information other states are collecting from providers and families and any specific assessment tools they are using, as well as how they track information from providers regarding these outcomes. Fourteen states responded to our survey. Specific questions include:

- How are other states' ASD benefit programs designed and implemented? What types of treatments are allowed and at what intensity and duration? Do other states allow for treatment in community and home settings, or just in clinical settings? What types of providers are eligible to serve children under other states' ASD benefit programs?
- How do states measure progress for children who have been diagnosed with an ASD who are receiving treatment? Do states use any forms/tools they developed and/or formal or standardized assessment tools to measure individual child progress? What types of information are collected from providers and families?
- Are there any rigorous evaluations or research of other states' ASD benefit programs overall?

We found there are already state profiles available in multiple places that outline states' program features, including approved treatment modalities, the specific nature of the funding stream that pays for the benefit, the amount of funding that is allocated toward the benefit, licensure requirements for providers, and other information. See the References section for more information about these existing resources.

## State survey responses and information about other states' ASD benefit programs

In our research, we did not find any one source that lists all of the information we were seeking for every state. However, there are several resources that families, practitioners, and other stakeholders can use in order to find specific information about benefits, statutes, mandates, waivers, and other resources available. Of those that we found, the resources below were the most comprehensive. Please see the Appendix for more information.

### *Federal requirements for states to provide treatment for Autism Spectrum Disorder*

The Center for Medicare and Medicaid Services (CMS) dictates that treatment for ASD is a required Medicaid state plan benefit under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Program. In July 2014, CMS issued a letter to state Medicaid directors advising them of this change (DeLillo, Houchens, & Cunningham, 2015). This letter also stated that Medicaid plans must cover ASD treatment services that are deemed medically necessary for treating behavioral conditions (Mann, 2014).

In this directive, CMS did not provide an effective date for this coverage to begin, but encouraged states to complete their benefit designs quickly and not to delay or deny any medically necessary services. According to DeLillo et al. (2015), this means that states are not able to provide treatment for ASD under a waiver. As of 2016, almost all states have enacted ASD insurance mandates. The vast majority of these mandates were created legislatively, although a few were the result of lawsuits (Florida, Louisiana, and Washington) or other actions (Easterseals Office of Public Affairs, 2016).

State Medicaid programs vary dramatically in terms of eligibility criteria and benefits provided to eligible children, due to legislation, litigation, and new evidence for effectiveness of treatments (Maglione et al., 2016). Similarly, according to Easterseals, state mandates have very little consistency across states in what is covered – they differ by age of diagnosis, ages eligible for services, amount of coverage (hour or dollar limits), types of covered services, and types of insurance policies covered, which creates a complicated and limited system. This significantly inhibits access to services for individuals who have ASD (Easterseals Office of Public Affairs, 2016). Due to all of these challenges states are facing in actually implementing the ASD benefits, it is anticipated that it will take states a long time before they can establish effective systems of ASD benefit delivery, data collection, and evaluation.

Of note, CMS does not mandate coverage of ABA treatment, however ABA is a commonly used treatment modality for children with ASD. Therefore, some states that had elected to cover services through waivers are in the process of updating their Medicaid state plans to ensure that federal financial participation is available for expenditures for these services (Maglione et al., 2016).

There is a dearth of literature and evaluation around the topic areas we outline above. Other researchers have noted this in their studies measuring outcomes and conducting evaluations around ASD benefits (Miller, 2016; Noyes et al., 2015). This could be due to the recent rule changes that were put in place by the Centers for Medicare and Medicaid Services in 2014 (described above). It is possible that, due to these recent changes, states have had to reevaluate their current efforts regarding outcome and benefit effectiveness. Thus, most

of the research presented below occurred prior to this rule change. Ongoing research is needed to determine what states are doing in order to measure the effectiveness of their ASD benefits and whether or not the new EPSDT benefit is producing improved outcomes for children who have an ASD.

### State autism benefit oversight

Survey respondents were asked which state department or agency houses their state's autism benefit program. Three states reported their Department of Human Services oversees their state ASD benefits. Two states report this to be housed in their Department of Health, one said the benefit is housed in the state Department of Education.

Eight respondents provided some other type of response, including:

- Department of Children and Families, Children's System of Care
- Department of Community Health
- Department of Mental Health
- Department of Medical Assistance Services and the Department of Behavioral Health and Developmental Services
- Department of Public Health and Human Services
- State Medicaid Agency, Utah Department of Health
- Department of Social Services, the State Medicaid Agency

### How states designed and implemented their autism benefit programs

Due to the CMS rule change in 2014, all states are moving toward implementing their programs through EPSDT benefits instead of through waivers. Most states approve of providers using the ABA treatment modality. Although there was not one single source that identified each state's program design and implementation under the new CMS rules, there are several resources that families, practitioners, and other stakeholders can use in order to find specific information about benefits, statues, mandates, waivers, and other resources available. This information can be found on in the References section of this report.

Survey respondents were asked to select from a list or specify which treatment methods their states' autism benefit program covers. The most commonly mentioned treatment method was Applied Behavior Analysis (ABA) (10 out of 14 states). Three states report that the Early Start Denver Model (ESDM) is covered by their state benefit and one state

noted that the DIRFloortime method is covered. None of the states selected PLAY Project or Relationship Development Inventory Therapies as covered by their state autism benefit.

Respondents also had the option to specify other types of therapies covered by their states' autism benefits. Of note, evidence-based practices were specified by Connecticut and Montana as covered by their autism benefit. Other therapies that were specified by one respondent include: Habilitative Intervention (Idaho), EPSDT work authorizing the expansion of benefits that exceed the 30 units covered by MCOs (Delaware).

Respondents were asked whether or not their state's ASD benefit program allows services and treatments to be performed in-home or at centers. Nine out of 14 states said they allow treatment to occur both in-home and in center-based facilities. New Jersey and Idaho only allow for in-home treatment. Montana allows for in-home, community-based settings and also up to half of the time in a school or daycare setting. Louisiana and Kentucky reiterated that they do not have an autism-specific benefit.

Respondents were also asked if their state allows for treatment of other or related conditions to autism under their autism benefit program. Six out of 14 states said this is allowed under their autism benefit.

The six states that do allow for treatment of other or related conditions as part of their autism benefit were asked to list which conditions they allow treatment for under their benefit. States provided various answers to this open-ended question. Two states (Idaho and Virginia) listed "developmental disabilities" but did not specify which ones. One state each provided the following open-ended responses for conditions are allowed for treatment under their benefit:

> *The determination [of these conditions] is functional, not diagnostic. — Iowa*
>
> *Co-occurring mental health [conditions]. — New Jersey*
>
> *Conditions that are severe, chronic, and persistent and require treatment or services similar to those required for persons with ASD; are not attributable to mental illness or emotional disturbance; and manifest in each of the core ASD features. — Montana*
>
> *Rett's Syndrome, Asperger's Syndrome, other childhood degenerative disorders, other pervasive developmental disorders that are unspecified. — Georgia*

Of the states that allow for treatment of other conditions, the six respondents were also asked which conditions are the most commonly reported. One respondent did not answer the question. Respondents provided varying answers:

- Georgia and Iowa did not have this kind of information available at this time
- Idaho and Virginia reported intellectual disabilities
- Idaho reported ADHD and Epilepsy
- Montana listed neurodevelopmental conditions
- Virginia also reported other related developmental disabilities as the most commonly reported

Minnesota also provides EIDBI services for children who have been determined to have a related condition such as Aspergers Syndrome, Fetal Alcohol Syndrome, Fragile X Syndrome, or Williams Syndrome. There may be other diagnoses that qualify as related conditions, however, these tend to be the most common.

### *Provider shortages*

Nearly all (13 out of 14 states) respondents noted that their states are experiencing provider shortages that negatively impact service delivery. Montana does not have a provider shortage and noted that they answered this way because they do not have the data to indicate that there is a shortage.

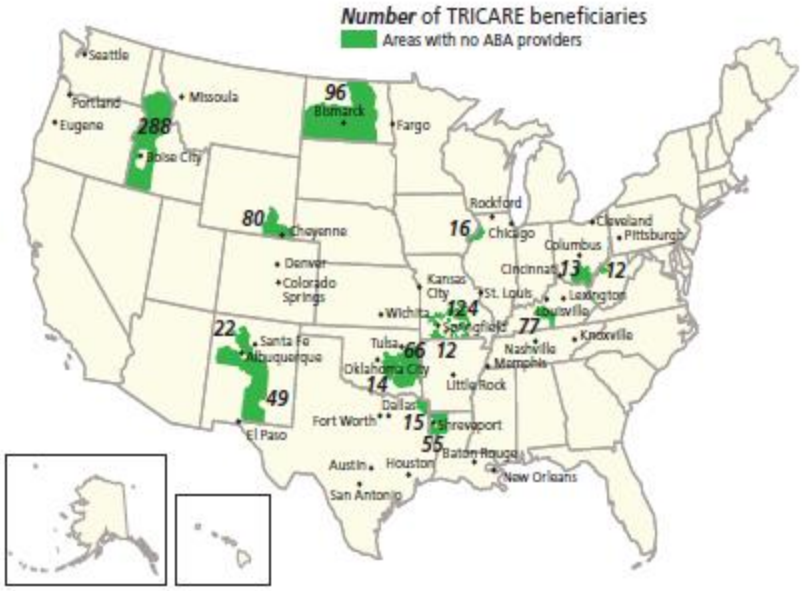
Two states (Alabama and Missouri) reported they have a provider shortage among licensed professionals, and four states (Connecticut, Idaho, Kentucky, and New Jersey) reported a shortage of direct treatment staff.

Seven states noted that they had more than one area of provider shortages. Of these:

- Five states (Delaware, Iowa, North Carolina, Utah, and Virginia) noted they had provider shortages regarding licensed professionals, supervisory staff, and direct treatment staff
- Georgia noted that 150 of 159 counties in their state are designated mental health professional shortage areas. They pointed out that there is also a shortage of Board Certified Behavior Analysts (BCBAs) for Applied Behavioral Analysis therapies.
- Louisiana noted that they have shortages of "both direct treatment staff and licensed personnel." They note that while their ABA program has grown dramatically in the past five years and continues to grow, there is still a need for more providers.

There were also similar findings from the literature review. States appear to be struggling to fully implement the new CMS rule change due to provider shortages. Provider shortages can lead to long waiting lists for families with children who have ASD, large caseloads for practicing providers, and other issues. The following map from Rand displays locations with potential TRICARE ABA users, but no board certified ABA providers (Maglione et al., 2016, p. 54).

**Figure 4.2**
**Map with Locations with Potential TRICARE ABA Users but No Board Certified ABA Providers with Major Cities Displayed**




Note: Number of potential ABA users in TRICARE, birth–18 years with ASD, in combined ZIP code locations with no ABA providers.

RAND RR1334-4.2

Note. From *TRICARE Applied Behavior Analysis (ABA) Benefit: Comparison with Medicaid and Commercial Benefits* (p. 54), by M. A. Maglione, S. Kadiyala, A. M. Kress, J. L. Hastings and C. E. O'Hanlon, 2016. Retrieved from RAND Corporation website: https://www.rand.org/pubs/research_reports/RR1334.html. Copyright 2016 by RAND Corporation. Reprinted with permission.

Additionally, 45 percent of respondents for Indiana's ASD gaps analysis reported that there is a service provider shortage in their area for family support services and specialty health and education services (HANDS in Autism, 2016). Michigan also reports provider shortages since the 2014 CMS rule change. According to Peters et al., (2014), as of July 2014, there were 240 certified behavior analysts in Michigan, but fewer than half of those treated individuals with ASD compared to an estimated 16,000 children in Michigan public schools who have an ASD diagnosis; the authors note that many more are focusing their work on treating individuals with ASD now that they can be reimbursed for ASD-related services. The authors also note that behavior analysts can have a caseload between 6-24 patients at a time, which depends on case complexity and additional supports (Peters et al., 2014). Private insurance and Medicaid/MIChild autism mandates have limitations on the type of provider that can diagnose ASD. While this helps to ensure that children are properly diagnosed and receive effective treatment plans, requirements for members to use designated centers – combined with the limited number of these centers–have resulted in many Michigan insurers putting many children who need a diagnosis and treatment plan on waiting lists, which have an average wait time of nearly five months for treatment (Peters et al., 2014).

DHS also reports provider shortages (Minnesota Department of Human Services, 2018). One component of the EIDBI evaluation is to explore the availability of ASD providers in Minnesota as well as the opportunities and challenges of becoming and maintaining status as an EIDBI provider. Specifically, we want to examine programmatic or regulatory factors that may create a disincentive for providers to become EIDBI providers. We also want to measure the effect the provider shortage has had on families, especially those who are located in Greater Minnesota and those who come from underserved cultural communities. More research is needed to determine to the extent and nature of the provider shortage in Minnesota.

### *How states assess the progress and outcomes of children who receive treatment through their ASD benefit program*

As a part of the state scan, we examined what other forms and information states were collecting from providers similar to the information that Minnesota collects from the CMDE and ITP forms. Ten out of 14 state survey respondents noted that their state does not conduct evaluation around CMS EPSDT-related ASD benefit programs.

**Four out of 14 states (Iowa, Louisiana, Montana, and New Jersey) noted that their state conducts evaluation of their state-administered benefit programs.**

These four states were asked how their state measures progress for children who have been diagnosed with an ASD and who are receiving treatment and provided the following answers:

- **Iowa** noted there is not a standard statewide measure and that varies by the choice of the clinician.
- **Connecticut** reported that they review treatment plans and adaptive behaviors for medical necessity purposes every six months.
- **Louisiana** reported they currently do not have an autism-specific benefit, however, behavioral health professionals with the five Managed Care Organizations contracted by the state reviews each individual ABA treatment plan to determine progress.
- **New Jersey** measures progress using Functional Behavior Assessments (FBA) and Behavior Support Plan (BSP) templates and works with an outside contractor, PerformCare New Jersey, to complete all of the clinical reviews. The PerformCare New Jersey clinical team reviews the BSP every 90 days (with the original or most recent FBA) for each child receiving ABA services. There are no pre-defined or determined rating scales, rather the state relies on the clinical expertise of the reviewers to make determinations. New Jersey also developed an ABA advisory group made up of 6-9 BCBA-Ds who assist the reviewers with any complicated situations that may arise in their practices.

### *Assessment tools for progress monitoring*

Additionally, the survey asked respondents to identify the types of assessment tools their state uses to measure progress. States use a variety of different assessment tools to measure progress. They also vary in what types of information they collect from these tools (Figure 1).

#### 1. Assessment tools used for progress monitoring by state

| State | Assessment tools used | Information collected |
|---|---|---|
| Iowa | Autism Treatment Evaluation Checklist (ATEC); Functional Analysis Interview (FAI); Functional Assessment Screening Tool; Verbal Behavior Milestones Assessment & Placement Program | Iowa does not collect assessment information as this is done by providers. The state has access to client-level data as needed. Eligibility determinations are made by program—some are made by state employees or contractors working on behalf of the Medicaid fee-for-service program and others are made by MCOs for Medicaid members who are also MCO members. |
| Louisiana | No specific assessment tool, but require a Comprehensive Diagnostic Evaluation. | Louisiana collects a clinical, developmental, and psychosocial history for the benefit recipient with a parent or caregiver of and a review of their records. State-licensed providers complete direct observation of the benefit recipient including assessment of current functioning of social and communicative behaviors and play or peer interactive behaviors using a valid DSM-V diagnosis. The state also tracks the justification/rationale for referral/non-referral for an ABA functional assessment and possible ABA services for a potential patient as well as recommendations for any additional treatment, care or services, specialty medical or behavioral referrals or consultations, and/or any additional recommended standardized measures, labs or other diagnostic evaluations considered clinically appropriate and/or medically necessary. |
| Montana | Vineland II, or newer edition, and any other autism-specific assessments. | Montana collects information about adaptive and autism-specific behaviors. |
| New Jersey | Functional Behavior Assessments (FBAs) are used to initiate treatment and Behavior Support Plans (BSPs) with data. These are conducted every 90 days and submitted for clinical review and continued authorization for ABA services. | The state utilizes a FBA tool which includes interviews with families, teachers, and observes the youth to create a treatment plan and details on the behavior support plans (BSP). |

### *Forms for providers*

The four states that conduct evaluation and progress monitoring (Iowa, Louisiana, Montana, and New Jersey) were asked if they have any required forms that providers need to complete in order for their clients to receive their state's ASD benefit. New Jersey has forms that providers are required to fill out, which they developed on their own. These are functional behavior assessment (FBA) and behavior support plans (BSP).

The FBA form is similar to the ITP and CMDE forms that Minnesota uses to measure progress for children who receive the EIDBI benefit both in length and content. The 22-page form asks for background information about the child, including demographic and background information, assessment tools used and findings, current behavioral interventions and responses to treatments, interviews and observations, behaviors exhibited by the client, and desired outcomes and goals. The FBA form also notes whether or not a client should receive ABA treatment, the setting, intensity and justification for the recommendation. Most of the fields in the FBA form are in the open-ended format.

The 12-page BSP form has similar content to the FBA form, but differs a bit from the content of the CMDE and ITP forms used by Minnesota. The BSP form tracks specific behaviors that are targeted for reduction, the function of those behaviors (i.e., the motivation as to why a client/child performs these behaviors), the ways in which providers and clients are working to minimize these behaviors, any new skills to be developed as a result, goals for obtaining these objectives, and progress updates (which are required to be measured every 90 days per the form). Most form fields are in the open-ended format.

Iowa, Montana, and Louisiana said they do not have any required forms for providers to complete. However, staff from Louisiana indicated that they have suggested, but not required, forms for their providers to complete. Furthermore, Louisiana plans to develop a Behavioral Treatment Plan template and they are also in the process of testing a supplemental diagnostic form.

In our literature review, we found that Maryland and New York conducted rigorous evaluation studies to assess the impact of benefits on children who have been diagnosed with an ASD. Although these evaluations were completed or used data and information prior to the CMS rule change, these evaluation approaches can inform Minnesota's EIDBI evaluation. Below are some examples of tools that researchers from these states used to evaluate and assess outcomes in children who have an ASD diagnosis.

### Maryland 1915(c) waiver evaluation (2015)

From June 2011 to May 2012, Eskow et al. (2015), evaluated Maryland's HCBS waiver programs (1915(c)) which allowed them to administer benefits and tailor services to children with an ASD. Researchers used propensity score matching to compare 130 families with children who have an ASD who received waiver benefits to 130 families waiting on the state registry for ASD services (this served as a control group).

The Maryland Autism Services Survey (MASS-R)—Revised Edition was designed to be completed by a parent/guardian or other parental figure and is the property of the Maryland Department of Education and the Beach Center on Disability at the University of Kansas (Eskow et al., 2015). It is important to note that the MASS-R is an "extensive survey" but only a subset of questions were applicable for the study. Researchers collected data on the following: waiver status, sex of the child, age of child with ASD measured in years, family income, and years the child with ASD has received waiver services or been waiting on the registry.

Researchers also measured the severity of the child's ASD using five Likert-based items including: difficulty with academic performance, independent living skills, communication skills, relationships with peers, and problematic behavior (Eskow et al., 2015). Additionally, the perceived child improvement over the last year was measured in the same five domains as the ASD severity index (i.e., academic performance, independent living skills, communication skills, relationships with peers, and problematic behavior). Ratings of improvement were based on a three-level Likert-based scale and using the Family Quality of Life Scale (Eskow et al., 2015).

Results indicated participants who were in the waiver group (and who were receiving benefits) reported more improvement regarding independent living skills and family quality of life over the last year compared with those on the registry who were not receiving services. These results suggested that Maryland's waiver program was promising for improving child and family functioning (Eskow et al., 2015).

### New York State Department of Health: Evaluation of the impact of early intervention services on young children with ASD and their families (2016)

In 2013-2014, New York State's Early Intervention Program (NYSEIP) provided services to over 8,000 children with ASD. The overarching goal of this study was to model an approach to evaluating the impact of participation in Early Intervention Programs (EIPs) on children with ASD and their families that can be used in New York, other states, and nationally for program evaluation and quality improvement purposes (Noyes et al., 2015). The researchers collaborated with a diverse group of stakeholders in early intervention outcomes for children with ASD in three phases. Phase I included identifying ASD-focused

child and family outcomes using concept mapping. Phase II included garnering a sample of children with ASD and their families as well as a comparison sample of children with other disabilities and their families in order to pilot and evaluate parent report measures of EIP impact on children with ASD and their families. Phase III included the sample of children with ASD and their families only to evaluate the impact of EIP services on children with ASD and their families (Noyes et al., 2016).

During Phase I of the study, researchers used Concept Mapping to generate 105 ASD-specific child and family outcomes (54 outcomes related to children and 51 family-related outcomes) to measure for the study. All 105 of these outcome items were integrated into their tools, the New York Impact on Family Scale (NYIFS), and the New York Impact on Child Scale (NYICS) for the purposes of Phase II of the study (Noyes et al., 2015). Concept mapping involves brainstorming, rating, and sorting priorities that parents, providers, coordinators, government officials, patients who have ASD, and other stakeholders believe should be measured as part of the study. They gathered information from stakeholders representing diverse perspectives to identify ASD-specific child and family outcomes expected to be achieved through participating in New York's Early Intervention Program (Noyes et al., 2015).

Researchers in New York also used the following tools to measure the outcomes identified during the Concept Mapping phase of the project:

- ***PDD Behavior Index (https://www.parinc.com/Products/Pkey/318)*** (completed at entry/exit)—a standardized measure of behaviors associated with Pervasive Developmental Disorders, including ASD.
- ***Parenting Stress Index Short Form (https://www.parinc.com/Products/Pkey/333)*** —identifies dysfunctional parenting and predicts the potential for parental behavior problems and child adjustment difficulties within the family system
- Family Outcomes Survey (FOS): Section A—used to assess family outcomes
- New York Family Survey Modified (NYSF-M)—used to assess family outcomes and completed at the exit
- Teacher PDDBI—completed by teachers/school staff

Researchers also completed a clinical record review for each study participant (Noyes et al., 2016).

The study results demonstrate that children with ASD showed improvement during their participation in the NYSEIP. Specifically, over 61 percent of children with ASD showed improvement both in overall developmental progress and at least 54 percent experienced a reduction in ASD symptoms (Noyes et al., 2016). One important finding is that the intensity of service coordination services negatively impacted the probability of a child's improvement (except when controlling for the delay in initiation of other EIP services). This finding points to the importance of ensuring timely access to EIP services as contributing to the probability of improvement in toddlers with ASD (Noyes et al., 2016).

Importantly, enrollment in the Medicaid program while participating in the NYSEIP was found to have a significant negative effect on the probability of a child's improvement. The probability of improvement by exit from the NYSEIP for children with ASD in this study was 18 percent lower than other study participants not enrolled in Medicaid (Noyes et al., 2016).

### *How states evaluate the impact of their autism benefit program overall*

We also explored if and how states are evaluating their ASD benefits and how these programs are having an impact on those children who receive them overall.

When state directors and policy specialists were asked in the survey whether or not their state's CMS EPSDT autism (ASD) benefit program had been evaluated in any way, 12 out of fourteen states responded that this had not been done.

This lack of global or aggregate evaluation is also noted in the research literature. For example, Miller (2016) reported that given the limited number of published studies on program evaluation with behavioral providers, their research team conducted an email survey, which was sent to providers in California and Texas in an attempt to gain more information from practitioners. Eighteen out of 20 providers in this study reported using internal staff to collect data for evaluation purposes, and all providers reported using individualized client goals as benchmarks for client progress. Six providers also reported collecting some data on process goals, four providers on outcome goals, and three providers on impact goals. Furthermore, none of these providers reported presenting evaluation data in publications or presentations or making the results available on their websites. Four providers reported using the information to make internal improvements, and four providers reported sharing data with stakeholders.

# Issues to consider

Based on the findings from the report sections above, we believe DHS should consider the following issues as we continue with the EIDBI benefit program evaluation.

## Ongoing research and collaboration with other states to inform Minnesota's EIDBI benefit program evaluation

We plan to share what we have learned from our field scan so in the near future via a series of webinars with other states. Since there is a dearth of literature and evaluation around ASD benefits, there was considerable interest among the states we surveyed to share ongoing progress of the evaluation. We are also exploring the creation of a national network or learning collaborative for states to share best practices, advice, and ideas specific to benefit evaluation. To engage states in this work, we could hold follow-up conference calls and web-based/ITV listening sessions to guide discussions with other states around important topics. As we suspect, and given that the CMS rules changed in 2016, it is possible that states are just figuring out how to implement the new rules for autism benefits and, like Minnesota, are just in the beginning stages of evaluating their benefits. We believe that it would be beneficial for us to continue to pursue information from other states in order to continue to increase knowledge and collaboration and to inform other areas of our project (such as the learning collaborative and ITP/CMDE form re-design).

It appears that Minnesota may be leading the charge with regard to ASD benefits evaluation. Also, other states may be struggling to get their initiatives off of the ground due to the changing landscape of CMS rules and litigation that is happening at all levels. We would be happy to discuss ways that we can provide leadership and initiate collaboration and information sharing across states (see specific suggestions below).

## Explore the development of a tool or process that will assess a child's progress over time in ASD treatment

One particular topic of interest among both the Learning Collaborative members and the research team is exploring some kind of tool(s) or process to assess a child's progress over time that begins when they become EIDBI beneficiaries in order to determine if their progress improves while they are receiving the benefit.

During our scan, a few states requested that we share the information and results of our evaluation. Since **12 out of 14** states do not conduct aggregated ASD benefit evaluation, perhaps Minnesota could lead the way in a cross-state information sharing and learning collaborative specifically geared toward evaluation and information.

Additionally, Wilder could investigate national organizations of states (government, nonprofit, or other) doing this work and connect with them in order for us to share our findings or gather information using this resource. Together, we could present or facilitate a session at relevant conferences or similar venues. We will investigate this further as we begin to convene a national collaborative.

## Gather more information about the experiences of providing and receiving the EIDBI benefit from stakeholders

Additionally, we want to learn more about the experiences of participating in the EIDBI benefit program from the perspective of the client/child with ASD, parents/family members and caregivers, as well as providers. We could go about this in a variety of ways. First, we could conduct a journey mapping process. This qualitative research method traces the path that stakeholders take as they navigate becoming EIDBI beneficiaries (or helping their clients or children/family member to do so) via key informant interviews and focus groups. After collecting this information, we would produce a visual map of the entry, high, and low, and exit points of their journey of becoming (or not) an EIDBI beneficiary. This will allow for DHS and other stakeholders to see what is working for families with the current systems and structures and where families may need some additional assistance along the path toward becoming a beneficiary.

Similar to the New York evaluation, we propose conducting Concept Mapping in order to determine outcomes to evaluate the impact of early intervention services on young children with ASD. Concept Mapping could take place within Minnesota's Learning Collaborative (which would be on a much smaller scale compared to what researchers did as part of New York's Early Intervention Program). Similarly, this could help us gather information from stakeholders representing diverse perspectives to identify child and family outcomes that are expected and/or hoped for through participating in Minnesota's EIDBI benefit program.

## Consider treatment modalities and their evidence base for coverage under the EIDBI benefit

Minnesota should consider which treatment modalities should be covered under its EIDBI benefit, particularly in light of the evidence base supporting each one. Of particular note is RDI, which lacks an evidence base to support it. We will continue to conduct research around the most effective treatment modalities and best practices for ASD-related treatments and therapies. Additionally, we will continue to look to the Learning Collaborative to provide guidance and advice regarding specific treatment modalities that should be covered under the EIDBI benefit.

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# Treatment Modality Information

Those interested in learning more about treatment modalities can visit their affiliated websites, found at the following web links. It should be noted that these websites are frequently created by those who have developed or trademarked a therapy modality, and the information and evidence provided on these web sites has not necessarily gone through rigorous fact-checking or a peer review process. Caution should be used when reading information provided on these websites.

**ABA**

- Association for Behavior Analysis International https://www.abainternational.org/welcome.aspx
- Behavior Analyst Certification Board https://www.bacb.com/
- Minnesota Northland Association for Behavior Analysis https://www.mnaba.org/

**DIR®/Floortime™**

- The Greenspan Floortime Approach https://www.stanleygreenspan.com/
- The Floortime Center http://www.thefloortimecenter.com/

**PLAY Project**

- The PLAY Project https://www.playproject.org/

**Early Start Denver Model**

- Early Start Denver Model https://www.esdm.co/

**RDI**

- RDIconnect™ https://www.rdiconnect.com/

# Assessment tools used

Articles referenced in this report noted using the following assessment tools for children and their parents/caregivers:

**Applied Behavior Analysis (ABA)**

- Autism Diagnostic Interview – Revised
- Autism Diagnostic Observation Schedule
- Bayley Scales of Infant Development
- Behavior Flexibility Rating Scale
- Child Behavior Checklist
- Childhood Autism Rating Scale
- Children's Communication Checklist
- Clinical Evaluation of Language Fundaments
- Early Social Communication Scales
- Gilliam Autism Rating Scale
- Intelligence Quotient (IQ)
- Mean Length of Utterance
- Mental Development Index
- Merrill-Palmer Scales of Mental Tests
- Mullen Scales of Early Learning
- Parenting Stress Index
- Preschool Language Scale
- Repetitive Behavior Scale
- Screening Tool of Feeding Problems
- Sequenced Inventory of Communication Development
- Skills™ Assessment
- Social Skills Rating Scale
- Stanford-Binet Intelligence Test
- Symbolic Play Test
- Vineland Adaptive Behavior Scales
- Wechsler Intelligence Scale for Children

**Early Start Denver Model (ESDM)**

- Autism Diagnostic Interview
- Autism Diagnostic Observation Schedule
- CHARGE Family Characteristics Questionnaire
- Early Screening of Autistic Traits Questionnaire
- Infant Toddler Checklist
- Intelligence Quotient (IQ)
- MacArthur-Bates Communicative Development Inventory
- Modified Checklist for Autism in Toddlers
- Mullen Scales of Early Learning
- Parent Sense of Competence Scale
- Questionnaire on Resources and Stress
- Repetitive Behavior Scale
- Social Communication Checklist
- Vineland Adaptive Behavior Scales

**DIRFloortime® and PLAY Project™**

- Achenbach Scales
- Child Behavior Rating Scale
- Childhood Autism Rating Scale
- Functional Emotional Assessment Scale
- Functional Emotional Developmental Questionnaire
- Maternal Behavior Rating Scale
- MacArthur-Bates Communicative Development Inventory
- Parenting Stress Index

**Relationship Development Intervention® (RDI)**

- Autism Diagnostic Interview - Revised
- Autism Diagnostic Observation Schedule
- Intelligence Quotient (IQ)

## Acknowledgements

The authors would like to thank…

**Minnesota Department of Human Services**
Nicole Berning
Gerry Nord
Guy Vogt
John Wiersma

**University of Minnesota**
Suma Jacob, MD, Ph.D.

**Wilder Research**
Mark Anton
Sheila Bell
Jenny Bohlke
Jackie Campeau
Phil Cooper
Amanda Eggers
Rachel Fields
Edith Gozali-Lee
Bryan Lloyd
Heather Loch
Kerry Walsh

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