“I HAVE NO VOICE. MAY I PLEASE BORROW YOURS?” AN OVERTURE FOR EXPANDING CHILDREN’S ACCESS TO INTELLECTUAL AND DEVELOPMENTAL DISABILITY SERVICES IN THE STATE OF NORTH DAKOTA

JONATHAN J. O’KONEK*

“But those with whom you can share the love and appreciation you have for your child are to be treasured. Life will be different for you, and life will be harder, not easier, for your child; but great, big-picture opportunity exists herein. Find your community.”[1]

ABSTRACT

All children deserve to grow and thrive in an environment that promotes their physical, emotional, and educational development. Children with Intellectual and Developmental Disabilities (“IDD”) face unique challenges, which can be ameliorated through the implementation and execution of state sponsored developmental disability and special education services programs. However, parents of children with an IDD condition often navigate the complicated and byzantine world of developmental disability eligibility laws without sufficient education or guidance. As a result, parents of children with an IDD condition may either: 1) not know about existing developmental disability services programs; and/or 2) fail to understand how their child’s IDD condition meets established eligibility criteria to obtain access to these programs. Both the federal government and the State of North Dakota have

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*† Assistant United States Attorney, United States Attorney’s Office, District of North Dakota, Bismarck, North Dakota since 2016. The author is the father to a wonderful son, named Sheamus, who lives with a challenging medical condition and several developmental delays. Additionally, the author is a United States Army veteran, a children’s book author, and a non-fiction story writer who strives to assist others with overcoming difficult circumstances by promoting compassion, honesty, and problem solving. The views and opinions expressed in this article are those of the author and do not necessarily reflect the official policy or position of the Department of Justice, the United States Attorney’s Office for the District of North Dakota, or any agency of the United States government. The author dedicates this article to Sharon Zastoupil, Sheamus’ Bismarck Early Childhood Education Program (“BECEP”) Early Intervention (“EI”) coordinator, and Courtney Pittmann, Sheamus’ Developmental Disabilities Program Manager (“DDPM”), for their ever-present, selfless, and warmhearted support of Sheamus through his developmental disability challenges. The author would also like to thank Roxane Romanick for educating the author about North Dakota developmental disability law and policy as he wrote this article. Finally, the author would like to thank his wife, Wendy O’Konek, for her continued love and support and for always advocating for Sheamus’ developmental needs.

[1] CHANTAL SICILE-KIRA, AUTISM SPECTRUM DISORDER: THE COMPLETE GUIDE TO UNDERSTANDING AUTISM 33 (Rev. ed., Penguin Group 2014) (2004) (quoting Michael John Carley, *Food for Thought: Parents Attitude is Everything*).

enacted laws which establish certain threshold intellectual and developmental disability eligibility criteria that children with an IDD condition must meet before obtaining access to developmental disability services. However, these laws have their own unique and stringent qualification standards, which have the practical effect of denying developmental disability services to North Dakota children who may have an IDD condition, but do not meet the established threshold criteria. As a result, in North Dakota, gaps exist which limit children with an IDD or an IDD condition from obtaining access to intellectual and developmental disability services, which negatively affects these children's growth and development. This article advocates amending current North Dakota intellectual and developmental disability criteria to eliminate these gaps and to expand access to special education and developmental disability services to all North Dakota children who have an IDD.

I. INTRODUCTION

A. INTELLECTUAL AND DEVELOPMENTAL DISABILITIES VIEWED THROUGH THE EYES OF A CHILD

Imagine you are an eighteen-month-old child residing in North Dakota who lives with a developmental disability. Presently, your parents do not yet know about your disability. However, within the past few months, you have heard your parents comment about how you are not meeting certain developmental “milestones.”[2] For example, you may hear them discuss with other people how you are a “late talker,”[3] that you “do not make eye contact or smile,”[4] or that you “do not use certain gestures like waving good-bye.”[5] Due to your age and the nature of your developmental disability, you are unable to verbally communicate your physical or mental challenges to either your parents or to medical professionals.[6] You listen as your parents become

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[2] *Id.* at 22 (articulating how babies with autism spectrum disorder (ASD) “will develop normally and then start to regress at around eighteen months,” meaning that they will not meet further developmental milestones); *see* LARA DELMOLINO & SANDRA L. HARRIS, ESSENTIAL FIRST STEPS FOR PARENTS OF CHILDREN WITH AUTISM 10 (Sandra L. Harris ed., 1st ed. 2013) (describing how children with ASD will generally have “delays in speech and language . . . poor eye-contact [and] limited interest in social interaction and other people’s smiles”).

[3] SICILE-KIRA, *supra* note 1, at 23-25 (One behavior exhibited by children with ASD is that they do not develop speech or, in the alternative, develop speech then regress and lose it.); DELMOLINO & HARRIS, *supra* note 2, at 10.

[4] SICILE-KIRA, *supra* note 1, at 25 (stating that children with autism spectrum disorder may make “[l]ittle or no eye contact” and may be “[d]etached from [the] feelings of others.”); DELMOLINO & HARRIS, *supra* note 2, at 11 (explaining that children with ASD may have “continued difficulties with eye contact”).

[5] DELMOLINO & HARRIS, *supra* note 2, at 11-12 (“Problems with ***using gestures*** to communicate become increasingly obvious as children with ASD get older . . . . Waiving ‘bye-bye’ is a good example of a simple gesture that typically developing children learn quickly, but may take some time for children with ASD to master.”).

[6] *See* SICILE-KIRA, *supra* note 1, at 23-24.

increasingly concerned about your development, only to hear their friends or relatives reassure them "not to worry" and that you will learn to "grow out of it."[7] However, as more time passes, your parents continue to worry about your developmental delays. You see them struggle to identify your particular developmental disability, to find possible developmental disability services, and to obtain—for you—therapies and intervention treatments.

At last, your parents apply for and receive early intervention services on your behalf.[8] When you celebrate your second birthday, you have received six months of early intervention services. You have thoroughly enjoyed meeting and playing with multiple therapists who have engaged in a team approach with both you and your parents.[9] During these six months, through the implementation of these developmental disability early intervention services, you have made important strides in your mental and physical developments.[10] You see your parents begin to laugh and smile more, and you become accustomed to your new routine. However, shortly thereafter, you hear your parents again worry about what will happen when you turn three-years-old.[11] You watch as they—and you—meet with multiple doctors, social workers, and psychologists who discuss your "eligibility" for continued disability services.[12] As you prepare for your third birthday, instead of feeling the excitement of a new year of creative goals and objectives, you feel the stress and fear your parents exhibit about whether you will receive continued services.[13] Due to your developmental disability, you have no voice—literally or figuratively—in this process. Instead, you

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[7] *Id.* at 21 ("When voicing these concerns to relatives, friends, or neighbors, the parent will often hear things like, 'She'll grow out of it.'").

[8] *See* 20 U.S.C. § 1400(a) ("Individuals with Disabilities Education Act."); *see also* N.D. ADMIN. CODE § 75-04-06 (2018) ("Eligibility for Intellectual Disabilities – Developmental Disabilities Program Management Services.").

[9] DELMOLINO & HARRIS, *supra* note 2, at 24-27 (explaining that providing early intervention services to children aged eighteen to thirty months who were diagnosed with ASD may reduce core symptoms of ASD. Specifically, these intervention services focus on providing "a warm and supportive environment that encourages very young children and their parents or teachers to interact with each other").

[10] *Id.*

[11] *Id.* at 56 ("When your child is approaching three years of age, you and her EI [early intervention] team will plan for her to make the transition out of early intervention and into the educational system."); *see* N.D. ADMIN. CODE § 75-04-06-02.1 (2018) (explaining North Dakota's eligibility paraments for children aged "three and above" to receive services under the North Dakota "Intellectual Disabilities - Developmental Disabilities Program Management Services.").

[12] DELMOLINO & HARRIS, *supra* note 2, at 56 ("As with early intervention, there is a process that children need to go through to establish their eligibility for preschool services . . . . Your child will be evaluated by a team of specialists to determine whether she has delays or a disability that will have an educational impact on her."); *see* N.D. ADMIN. CODE § 75-04-06-02.1(1)(a) ("A diagnosis of the condition of intellectual disability must be made by an appropriately licensed professional using diagnostic criteria accepted by the American psychiatric association.").

[13] *See* SICILE-KIRA, *supra* note 1, at 205-09 (giving parents tips for navigating the IEP process).

must borrow the voices of your parents, caregivers, psychologists, and social workers to speak on your behalf.[14] However, again, because of your developmental disability, many important pieces of information are lost in translation.[15] Ultimately, it will be up to your parents or guardians to translate as much information as possible about you and your specific developmental disability conditions, to be your voice, and to advocate on your behalf.[16]

B. INTELLECTUAL AND DEVELOPMENTAL DISABILITIES VIEWED THROUGH THE EYES OF A PARENT

When a parent learns that their child has a developmental disability, it is a life changing event.[17] For many parents, it is a day that they will always remember or, conversely, a day they will never forget.[18] Initially, when your child was eighteen-months-old, you noticed “suspicious” or “unusual” behavior. Nonetheless, you assured yourself—and others you trust assured you—that your child would “grow out of it.”[19] However, instead of “growing out of it,” your child’s development remained stagnant, or worse, regressed.[20] You begin to worry and now find yourself constantly observing your child to classify what this “unusual” behavior might mean. After many sleepless nights and bouts of worrying, you finally identify and apply for developmental disability services. After multiple evaluations and examinations, you learn that your child has an intellectual or developmental disability. From that moment forward, you and your child enter a new world fraught with a plethora of challenges.[21] Additionally, the unspoken truth is that you and your child will, consequently, struggle to overcome these challenges.[22]

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[14] *Id.* at 190 (explaining how a parent’s observations of their “child’s abilities, challenges, and learning styles will clarify which educational strategies and therapies could be useful for [their] child”).

[15] *Id.* at 23 (“The doctor may be hesitant to jump to any conclusions, because not all reported observations are necessarily objective and they can be interpreted in different ways.”).

[16] *Id.* at 196-202 (offering parents advice in advocating for their child’s education).

[17] *Id.* at 67 (“The day a parent learns that his or her child has a disability is like one of those dramatic event days . . . . Even if the parent suspected that there was something wrong with the child, they can’t believe this is happening.”).

[18] *Id.* (“For every parent of a child with a disability, this moment is forever etched on their mind.”).

[19] *Id.* at 21.

[20] *Id.* at 22-25.

[21] Nathaniel Scherer et al., *Depression and Anxiety in Parents of Children with Intellectual and Developmental Disabilities: A Systematic Review and Meta-Analysis*, PLOS ONE, 1 (July 30, 2019), https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0219888&type=printable (“Although caring for a child with intellectual and developmental disabilities (IDD) can have positive outcomes, parents may be at a greater risk of depression and anxiety, due to a number of associated stressors, such as increased caregiver demands and financial strain.”).

[22] *See id.*

It is difficult to truly encapsulate the ever-present—and often overwhelming—daily challenges that parents of children living with an IDD face in raising and caring for their children.[23] These challenges include: frequent medical or therapy appointments, lack of caregiver support, increased financial costs and strain, haggling with insurance companies or governmental agencies, and the lack of time to complete work tasks or spend time with other family members.[24] Moreover, children with an IDD experience unique challenges depending on their individual diagnosis, conditions, and circumstances, so there is not a "one size fits all" approach to address these challenges.[25]

In the author's own experience, due to the tremendous amount of involvement in your child's care, being a parent of a child with an IDD is a test of endurance.[26] To advocate for—and provide support to—your child, you must become: a master at time management, a skilled negotiator, and a practicing stoic philosopher.[27] However, to accomplish these goals, you must completely immerse yourself into your child's developmental challenges, which can cause significant bouts of fatigue and unhappiness.[28] At times, you may feel completely underqualified to be the parent of a child with an IDD.[29]

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[23] *Id.* ("[A] number of chronic stressors are inherent in raising a child with IDD, such as child behavioural [sic] problems, high caregiver demands, stigma, and financial strain. As a result of these stressors, parents of children with IDD may be more vulnerable to depression and anxiety.") (footnotes omitted); NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, PARENTING MATTERS: SUPPORTING PARENTS OF CHILDREN AGES 0-8 230 (Vivian L. Gadsen et al. eds., 2016), https://nap.nationalacademies.org/read/21868/chapter/7#230 ("Parents, and indeed family members, of children with developmental disabilities experience challenges that differ from those experienced by parents of typically developing children.").

[24] *See* Scherer et al., *supra* note 21, at 1.

[25] *See* NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, *supra* note 23, at 230-31 ("Some children with disabilities pose particular challenges because of developmental needs and behaviors that require specific parenting skills or actions not required for children who are developing typically.").

[26] *See* Elise J. Matthews et al., *Tactics and Strategies of Family Adaptation Among Parents Caring for Children and Youth with Developmental Disabilities*, GLOB. QUALITATIVE NURSING RSCH. (June 29, 2021), https://journals.sagepub.com/doi/10.1177/23333936211028184 ("Systemic problems in the coordination and delivery of services mean that many parents of children with disabilities feel they must become highly involved in their child's care. For many, this entails becoming skilled advocates, topical experts, and system navigators.").

[27] *See id.*; *see also* NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, *supra* note 23, at 230 (quoting a mother from Omaha, Nebraska, "With a special needs child, a parent has to learn to be patient, to be a nurse, to be a lawyer because I have to be a good mediator for all the things that happen to my child.").

[28] *See* Awat Feizi et al., *Parenting Stress Among Mothers of Children with Different Physical, Mental, and Psychological Problems*, J. RSCH. MED. SCI. 145 (Feb. 2014), https://www ncbi nlm nih.gov/pmc/articles/PMC3999601/pdf/JRMS-19-145.pdf ("Having a child with developmental or psychological problems is always stressful for their parents who are taking care of them . . . . These parents, other than bearing financial pressures, are always facing emotional pressures such as feeling ashamed or feeling guilty.").

[29] JEN JACOB & MARDRA SIKORA, THE PARENTS GUIDE TO DOWN SYNDROME 19 (2016) (explaining that parents of special needs children may ask, "[h]ow did you get this job when you're *so* underqualified? Impatient? And anti-angelic? Well, now you know the secret. That magic wand

Additionally, others may inquire as to how you are able to work, function, and manage your child's needs.[30] In your head, you know you perform these tasks for your child because he or she completely relies upon you. In fact, you know you must live a different, and more challenging, life because you are the voice of a child who is unable to speak for himself.[31]

C. A ROADMAP FOR EXPANDING DEVELOPMENTAL DISABILITY SERVICES FOR CHILDREN IN NORTH DAKOTA

As a society, we must treat children who live with an IDD with dignity, respect, and compassion. The best way to ensure these children receive proper treatment is to empower local, state, and federal governments with the laws, service agencies, and funding to provide developmental disability services to these children.[32] For example, these services include in-home support, individualized therapy sessions—*e.g.,* speech, physical, or occupational therapies—special education programs, and respite care for parents. However, although federal laws authorize services to children with an IDD and their parents, it is the responsibility of each state to apply these federal laws through the laws in its own particular state.[33] Moreover, in applying federal law, each state has established unique eligibility criteria which children must meet to receive developmental disability services.[34] As a result, whether a child with an IDD will receive state sponsored services—and what services a child will receive—almost entirely depends on the state or local community in which a child resides.[35] This different application of federal law creates disparate treatment as applied to children with an IDD because they may meet eligibility criteria for developmental disability

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you thought parents of special needs get—they don't. It's true: No parent really knows how this whole thing works.").

[30] *Id.* ("People will now say to you how special you are to have a child with Down syndrome. You may smile and nod, like the millions of parents who are with you in the club, knowing that you're just as qualified, or unqualified, as the next person.").

[31] SICILE-KIRA, *supra* note 1, at 32-33.

[32] Feizi et al., *supra* note 28, at 146 n.12 ("Social support is a variable that mediate the effects of having an autistic child on the mental health of the mother and family's function.").

[33] *See* 20 U.S.C. § 1400; *see also* SICILE-KIRA, *supra* note 1, at 184-85 (describing, in 2009, the federal government "covered 16.9 percent of the estimated excess cost of educating children with disabilities").

[34] SICILE-KIRA, *supra* note 1, at 184 ("IDEA is a federal act, and each state may provide more special education rights than provided by IDEA, but a state may not take away rights that are provided under this act.").

[35] *Id.* ("Much costly litigation takes place between parents and school districts over the interpretation of what is considered an 'appropriate' education under the student's right to a 'free and appropriate education.'").

services in one state or community but not meet eligibility criteria in another state or community.[36]

This article advocates expanding the eligibility criteria for obtaining child developmental disability services in the State of North Dakota. The next section will explore the challenges that both children with an IDD and their parents face in their everyday lives. The third section will discuss how developmental disability services positively impact the lives of children with an IDD. Most importantly for this article, the fourth section will identify the applicable federal and State of North Dakota laws, which create both access to, and support for, developmental disability services. Thereafter, the author will evaluate the access gaps existing with North Dakota's developmental disability services and outline a proposal for changing the current North Dakota developmental disability laws to expand eligibility criteria. Finally, the author will conclude this article by providing a hopeful vision for the future.

II. CHALLENGES ASSOCIATED WITH RAISING AND ADVOCATING FOR CHILDREN WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY

A. PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES FACE CHALLENGES

1. Developmental Disability Defined

The term "developmental disability" encapsulates "a diverse range of cognitive and physical impairments, each of which emerge during early child development and remain present throughout a person's lifetime."[37] Specifically, in The Developmental Disabilities Assistance and Bill of Rights Act of 2000, the United States Congress defined the term "developmental disability" as "a severe, chronic disability of an individual" traceable to "a mental or physical impairment" or combination thereof, which occurs before the age of twenty-two years, that will likely "continue indefinitely," "results in substantial functional limitations" in three or more enumerated life areas, and reflects an individuals' need for specialized services and assistance.[38]

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[36] *See* Alvarez & Marsal, *North Dakota Developmental Disabilities Study Report and Oral Presentation*, 51-57 (June 2022), https://ndlegis.gov/files/committees/67-2021/23_5168_02000presentation1230.pdf.

[37] Scherer et al., *supra* note 21, at 1 (citing *Facts About Developmental Disabilities*, CDC, https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html (Apr. 27, 2022)).

[38] 42 U.S.C. § 15002(8)(A). The Act specifically enumerates seven major life areas: "(I) Self-care; (II) Receptive and expressive language; (III) Learning; (IV) Mobility; (V) Self-direction; (VI) Capacity for independent living; [and] (VII) Economic self-sufficiency." *Id.* at § 15002(8)(A)(iv)(I)-(VII)."

This Act further highlights the unique needs and circumstances of IDD children by explaining that:

> [a]n individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described . . . if the individual, without services and supports, has a high probability of meeting those criteria later in life.[39]

Fifteen percent of children aged three to seventeen years old experience a developmental disability which limit their ability to participate in everyday activities, for example, by impeding their communication, learning, or mobility.[40] The term "intellectual disability," which falls under the umbrella of developmental disabilities, is a "condition characterised [sic] by severe limitations in intellectual functioning and adaptive behaviour, [sic] impairing a person's ability to learn, understand, and apply complex information and skills."[41] Often, intellectual disabilities occur in conjunction with developmental disabilities and are referred to in concert as Intellectual and Development Disabilities or IDD.[42]

2. *Daily Support is Needed to Raise a Child with an IDD*

Children with an IDD require individuals to both support and advocate for their needs.[43] Specifically, children with an IDD often require in home caregiver support, unique therapies, medical treatments, and governmental social services designed to offset the cost of providing these special services.[44] In most cases, parents of children with an IDD are the primary advocate for obtaining support and services for their children.[45] However,

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[39] 42 U.S.C. § 15002(8)(B).

[40] Scherer, *supra* note 21, at 1; *see Increase in Developmental Disabilities Among Children in the United States*, CDC https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities html (May, 16, 2022) ("[S]cientists from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) found that 17% of children aged 3–17 years had a developmental disability, and importantly, that this percentage increased over the two time periods compared, 2009–2011 and 2015–2017.").

[41] Scherer, *supra* note 21, at 1.

[42] *Id.* at 2.

[43] Anne M. Ritzema & Ingrid E. Sladeczek, *Stress in Parents of Children with Developmental Disabilities over Time*, 17 J. ON DEVELOPMENTAL DISABILITIES 21, 22 (2011), https://oadd.org/wp-content/uploads/2011/01/41010_JoDD_17-2_21-34_Ritzema_Sladeczek.pdf ("Children who struggle with day to day activities such as eating and drinking, toileting, dressing, bathing, grooming, and health care, require support from a parent or caregiver to accomplish these tasks. For children with DD [developmental disabilities] this struggle is common and is often present across areas of daily living and across the lifespan.").

[44] *See id.* at 23.

[45] *See id.* at 22.

supporting and advocating for a child with an IDD requires a substantial amount of time and effort.[46] For example, in order to support a child with an IDD a parent or guardian will likely have to administer and manage their child's necessary and significant activities, such as those noted below:

- Scheduling and attending frequent medical appointments;[47]
- Participating in long distance, or out of state, travel to obtain their child's specialized medical or therapeutic services;[48]
- Making out-of-pocket payments for their child's necessary medical, therapeutic, or special educational products or services when not covered by insurance or financial assistance—and haggling with insurance companies over preapprovals, referrals, and coverage for medical expenses;[49]
- Engaging in intense education about their child's particular disability and how to assist with their development;[50]
- Enduring lack of sleep, frequent sleep interruptions, or ever-present fatigue due to taking care of the child's needs;[51]
- Worrying about their child's health and developmental delays, the difficulty of navigating byzantine disability services programs, and the uncertainty of obtaining state sponsored services;[52]
- Providing for the needs of other children in the family who may experience challenges adjusting to having a sibling with a developmental disability;[53]

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[46] Feizi et al., *supra* note 28, at 145 ("Parents of children with developmental problems are always bearing a load of stress."); Ritzema & Sladeczek, *supra* note 43, at 22 ("The added strain of performing more daily living tasks for their children with DD [developmental disabilities] than parents of typically developing children can lead to elevated stress in parents of children with DD.").

[47] *See* Matthews et al., *supra* note 26, at 5.

[48] *Id.* ("Lengthy travel to access services was a reality for parents who did not live near service locations.").

[49] *See id.* ("Families might pay out-of-pocket in order to get the right person or the right services when there was a long wait for public service or the family did not qualify for financial assistance.").

[50] *Id.* ("Parents reported many hours searching the internet for resources. Parents learned new skills (such as nursing care and therapies) while navigating the system, advocating for their children, fundraizing [sic], and providing care, akin to being a case manager.").

[51] SICILE-KIRA, *supra* note 1, at 134-35 (explaining how parents of children with ASD experience extreme fatigue); *see* Matthews et al., *supra* note 26, at 13 ("Research with parents of children with profound multiple disabilities (PMD) has highlighted how parents strive to protect their children at the cost of their own mental well-being.").

[52] *See* Alvarez & Marsal, *supra* note 36, at 52 ("We heard that people with disabilities and their families find the [North Dakota] system difficult to navigate. Different eligibility criteria, forms, and places to apply make it complicated to know where to go for help. In addition to goods and services, families need help with (1) information and navigation; and (2) connecting and networking with peers.").

[53] SICILE-KIRA, *supra* note 1, at 135, 165 ("Siblings can suffer from being raised in a family with a child who has ASD. Not only do they have a sibling who is hard to understand, has limited interests, and is not social . . . they also feel the stress their parents are under, as well as the fact that

- Experiencing guilt or shame over not being able to obtain the necessary services for their child or manage their competing obligations;[54]
- If the parent is employed, satisfying both their professional and family obligations, which may be interrupted by any of the aforementioned items or concerns.[55]

As a result of these stressful, daily challenges, in many cases, one or both parents of a child with an IDD will experience depression related symptoms.[56] Additionally, due to the daily demands of advocating for and supporting their child, one parent may have to leave or reduce their employment so that they can assume the role of in-home caregiver for their child.[57] Moreover, parents of a child with an IDD will experience a myriad of emotional and physical responses to these distinct challenges.[58] They may experience depression, burnout, and resentment.[59] As a result, parents must develop coping skills to both get through the day and to ensure that they are advocating for the long-term interests of their child.[60] Specifically, there are

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inevitably more of the parents' attention is taken up by the sibling with ASD.") ("On the down side, many siblings feel resentment at the extra attention the child with autism receives . . . . Many siblings feel anxiety about how to interact with their brother or sister [and] [o]ften there is a feeling of resentment at having to take on extra household chores, coupled with restrictions in social activities.").

[54] *Id.* at 135 ("Often families tend to isolate themselves either because of concerns over their child's socially inappropriate behaviors or from fear of being embarrassed by some of the child's behaviors . . . .").

[55] Matthews et al., *supra* note 26, at 9, 12 ("Parents described altering their work life—reducing hours, stopping work, or altering their schedule—to accommodate the needs of their children with DD [developmental disabilities] . . . . The parents we interviewed described adjustments to their home and work lives . . . [and] described how families of children with intellectual disabilities made accommodations in employment, schedules, and informal supports (especially extended family) to construct a daily family routine in which to realize their values, beliefs, and goals.").

[56] Scherer, *supra* note 21, at 14 ("The findings of this systematic review provide evidence that parenting a child with IDD is associated with elevated levels of depressive symptoms. Almost one third (31%) of parents of children with IDD in this review were estimated to experience moderate depression, 24% higher than the estimate for parents of children without IDD.").

[57] Matthews et al., *supra* note 26, at 9 ("Parents described altering their work life—reducing hours, stopping work, or altering their schedule—to accommodate the needs of their children with DD [developmental disabilities].").

[58] NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, *supra* note 23, at 230 ("When a child with one or more disabilities is born into a family or when parents receive the diagnosis of their child's disability, they often experience a range of emotions (e.g., shock, grief, anger) that are somewhat similar to those experienced upon learning about the death of a loved one.").

[59] *See* Sandra Maureen Marquis et al., *Mental Health of Parents of Children with a Developmental Disability in British Columbia, Canada*, J EPIDEMIOL CMTY. HEALTH 173, 176 (2020) https://jech.bmj.com/content/jech/74/2/173 full.pdf ("This study found that at the population level in BC [British Columbia] both mothers and fathers had significantly higher odds of a diagnosis of depression or another mental health problem following birth of their child with a DD [Developmental Disability], compared with mothers and fathers of children who did not have a DD.").

[60] DELMOLINO & HARRIS, *supra* note 2, at 139-44.

two separate, broad coping strategies that parents can adopt.[61] First, parents can employ "instrumental coping" strategies, which focus on implementing specific steps to overcome the challenges parents with special needs children face.[62] Additionally, parents can implement "palliative coping" approaches that focus on the parents' specific "feelings" about their child and their child's needs.[63] Employing these coping strategies can assist parents in overcoming the lifelong daily challenges that they and their child face.

B. CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES FACE LIFELONG CHALLENGES

Children with an IDD face challenges related to their specific, individual IDD conditions and diagnosis. Although there are many different types of IDDs, two common IDDs are autism spectrum disorder and Down syndrome.[64] The below listed paragraphs will provide a brief synopsis of the signs and symptoms of these conditions to better provide specific examples of the needs of children with an IDD.

1. An Illustration of Two Common Intellectual and Developmental Disabilities: Autism Spectrum Disorder and Down Syndrome

a. Autism Spectrum Disorder

Autism spectrum disorder ("ASD") is "considered a neurodevelopmental disability, meaning that it affects the functioning of the brain."[65] Additionally, ASD "typically appears during the first three years of life and is thought to be four times more prevalent in males than in females."[66] Moreover, due to the nature of ASD symptoms, "ASD is sometimes difficult to diagnose at a very early age."[67] As the name explains, ASD is a "spectrum" of characteristics that may be exhibited differently by one person on "one end of the spectrum" versus a second person who is on the "opposite end" of the spectrum.[68] As a result, "the severity of any given behavior or characteristic of autism can be present in a mild to severe degree

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[61] *Id.* at 139.

[62] *Id.*

[63] *Id.* at 140.

[64] Marisa Fisher et al., *Vulnerability and Experiences Related to Social Victimization Among Individuals with Intellectual and Developmental Disabilities,* 5 J. MENTAL HEALTH RSCH. IN INTELLECTUAL DISABILITIES 32, 34 (2012), https://www researchgate.net/publication/233467155_Vulnerability_and_Experiences_Related_to_Social_Victimization_Among_Individuals_With_Intellectual_and_Developmental_Disabilities.

[65] SICILE-KIRA, *supra* note 1, at 21.

[66] *Id.*

[67] *Id.*

[68] *Id.* at 24; DELMOLINO & HARRIS, *supra* note 2, at 4.

in any given individual."[69] Therefore, not everyone with ASD will exhibit the same type or severity of characteristics.[70] In general, a child with ASD exhibits behaviors falling within two broad categories: "Deficits in Social Communication and Social Interaction" and "Restricted, Repetitive Patterns of Behavior and Interests."[71] Specifically, some common characteristics exhibited by a child with ASD include:

- "[N]ot imitat[ing]others,"
- "Little or no eye contact,"
- "[N]ot develop[ing] speech, or develop[ing] an alternative method of communication such as pointing and gesturing,"
- "Repeat[ing] words or phrases instead of using normal language (echolalia),"
- "Prefer[ing] to be alone,"
- Having "[i]nappropriate attachment to objects,"
- Engaging in "[r]epetitive motor movements (rocking, hand flapping),"
- "[N]ot develop[ing] age-appropriate peer relationships," and
- Experiencing significant sensory processing related issues such as "cover[ing] ears" or "remov[ing] clothes often."[72]

The aforementioned list of behaviors and symptoms is not exhaustive and, ultimately, medical professionals will assess the number and severity of ASD symptoms prior to making a diagnosis.[73] In summary, children with ASD experience difficulties with social skills, communication, self-help skills, and behavioral and sensory challenges.[74] However, providing early intervention and other IDD related services to children diagnosed with ASD may reduce core symptoms of ASD and improve their long-term development.[75]

b. Down Syndrome

Down syndrome is "a common genetic condition involving the twenty-first chromosome,"[76] which causes "delay in physical, intellectual, and language development."[77] There are three different types of Down syndrome:

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[69] DELMOLINO & HARRIS, *supra* note 2, at 4.

[70] SICILE-KIRA, *supra* note 1, at 24.

[71] DELMOLINO & HARRIS, *supra* note 2, at 5.

[72] SICILE-KIRA, *supra* note 1, at 25-27.

[73] *Id.* at 24, 31.

[74] DELMOLINO & HARRIS, *supra* note 2, at 66-67, 76-77, 106-07, 122-23.

[75] *Id.* at 24-27.

[76] JACOB & SIKORA, *supra* note 29, at 10.

[77] *New and Expectant Parents: What is Down Syndrome? Fast Facts*, NAT'L DOWN SYNDROME CONG., https://www ndsccenter.org/programs-resources/new-and-expectant-parents/ (last visited Nov. 18, 2022).

Trisomy 21, Translocation Down syndrome, and Mosaic Down syndrome, which have their own expressions and characteristics.[78] Trisomy 21 is the most frequent type of Down syndrome, and it occurs at conception when each cell obtains "three copies of the twenty-first chromosome."[79] Translocation Down syndrome occurs when, during pregnancy, "part of the chromosome attaches to another chromosome," causing people with this form of Down syndrome to have "two copies of the twenty-first chromosome and another part of a twenty-first chromosome attached to another."[80] Finally, Mosaic Down syndrome develops "when not all cells have an extra copy of the twenty-first chromosome," which affects a wide and varied range of a person's cells.[81]

According to the National Down Syndrome Congress, "Down syndrome is one of the leading clinical causes of cognitive delay in the world [and] it is not related to race, nationality, religion, or socio-economic status."[82] Individuals with Down syndrome typically display certain physical attributes including "[d]ecreased or poor muscle tone . . . [f]lattened facial profile and nose . . . [u]pward slanting eyes . . . [and] [w]hite spots on the colored part of the eye."[83] However, not everyone who has Down syndrome will exhibit these physical characteristics.[84] Additionally, individuals with Down syndrome take longer to achieve developmental milestones in gross motor, language, and self-help or adaptive care.[85]

Typically, adults with Down syndrome will experience speech and language challenges, which will "cause the greatest challenge for creating relationships and pursuing social interactions."[86] However, it is important to remember that "[t]here is wide variation in mental abilities, behavior, and physical development in individuals with Down syndrome. Each individual has his/her own unique personality, capabilities, and talents."[87] Moreover, "[i]ndividuals with Down syndrome benefit from loving homes, early intervention, inclusive education, appropriate medical care, and positive public attitudes."[88]

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[78] JACOB & SIKORA, *supra* note 29, at 14.

[79] *Id.*

[80] *Id.*

[81] *Id.*

[82] *New and Expectant Parents: What is Down Syndrome? Fast Facts*, *supra* note 77.

[83] JACOB & SIKORA, *supra* note 29, at 54.

[84] *See id.* at 15-17 (explaining that individuals with Mosaic Down syndrome do not always exhibit the physical characteristics of Down syndrome).

[85] *Id.* at 121 (providing a "Milestone Comparison Chart," which juxtaposes the typical range for children to achieve developmental milestones to those children with Down syndrome who achieve these milestones later in life).

[86] *Id.* at 169.

[87] *New and Expectant Parents: What is Down Syndrome? Fast Facts*, *supra* note 77.

[88] *Id.*

2. *Challenges Experienced by Children with Intellectual and Developmental Disabilities*

Children with an IDD experience numerous challenges, which translate into adulthood.[89] Specifically, "[c]ompared to those without disabilities, individuals with intellectual and developmental disabilities (IDD) are at greater risk of experiencing abuse and social exploitation."[90] In fact, individuals with an IDD are twice as likely to experience crimes against their person and one and one-half times more likely to experience crimes against their property.[91] However, most often, individuals with an IDD experience minor injustices such as being mocked or teased.[92]

Notably, for children with an IDD, bullying is a major problem.[93] In fact, children with an IDD begin to experience bullying as early as elementary school, with the problem worsening as they attend secondary school.[94] Bullying occurs against children with an IDD for many reasons, including because they may look, act, and sound different than children without an IDD.[95] Importantly, bullying—whether in the form of verbal or physical abuse—has the practical effect of upsetting, scaring, and hindering the development of children with an IDD.[96] Therefore, needless to say, as a society, we must ensure that we never tolerate the bullying of children with an IDD, and we always interfere to stop any bullying when it occurs.[97]

Perhaps the best way to help children with an IDD overcome challenges, including challenges related to bullying, is to encourage individuals in our communities to utilize "People First Language."[98] In essence, to use "People First Language" means to employ "the conscious use of language to both avoid and prevent the dehumanization of people with disabilities."[99] In practice, this means choosing language that more accurately and empathetically describes a person with an IDD.[100] Thus, we should encourage individuals not to use language that defines a child by their IDD condition or conditions.[101] For example, people should state that an

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[89] Fisher et al., *supra* note 64, at 33.

[90] *Id.*

[91] *Id.*

[92] *Id.*

[93] SICILE-KIRA, *supra* note 1, at 228-30.

[94] *Id.* at 228.

[95] *Id.* at 229.

[96] *See id.* at 228.

[97] *Id.*

[98] JACOB & SIKORA, *supra* note 29, at 21.

[99] *Id.*

[100] *Id.* ("Language evolves, and consequently people, even professionals, may not consider or be aware of usages that are offensive.").

[101] *Id.*

individual *has* an IDD and not that they *are* an IDD.[102] Additionally, we should not state that individuals with an IDD are "suffering" from their IDD diagnosis or conditions.[103] By using "People First Language," we can help others see the unique gifts that children with IDD possess, change negative attitudes exhibited toward people living with an IDD, and choose to look at a person's individual character instead of relying on disparaging "throwaway words."[104]

However, in addition to "People First Language," individuals should be mindful of "Identity First Language," which has been described as the "opposite of people-first language" because it "emphasizes someone's disability as an embedded, inherent part of the person's identity, the front, and forefront of someone's personhood."[105] Individuals who use identity-first language each have different rationales for using this language "that are rooted in their own personal feelings about their disability."[106] For example, some individuals with disabilities "view their disability as an integral part of their being. They view it as a natural, or even prized facet, of themselves, and they use identity-first language to express such."[107] Therefore, it is important to always communicate with, and listen to, an individual who is living with a disability about which type of language they prefer. Even though individuals living with an IDD face lifelong challenges, as illustrated in the forthcoming paragraph, providing children who have an IDD condition with education, therapeutic, and intervention services provides extensive benefits to both these children and society.

III. THE POSITIVE IMPACT OF PROVIDING EARLY CHILDHOOD SERVICES TO CHILDREN WITH DEVELOPMENTAL AND INTELLECTUAL DISABILITIES

A. THE INDIVIDUAL BENEFITS OF PROVIDING INTERVENTION SERVICES TO CHILDREN WITH AN IDD

Multiple studies have shown that providing children who have an IDD with early medical, therapeutic, and educational services greatly aids their physical and mental development and has an exponential impact on their

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[102] *See id.* ("A person has Down syndrome—a person is not Downs; there are no 'Downs babies' or even 'Downs parents.'").

[103] *Id.*

[104] *Id.* at 22.

[105] Jill Feder, *Identity First Language*, (July 23, 2022), https://www.accessibility.com/blog/identity-first-language ("Identity-first language should be a linguistic staple of anyone who interacts with the disability community.").

[106] *Id.*

[107] *Id.*

long-term ability to manage their self-care.[108] In fact, children under the age of three who participate in early intervention services will receive educational and developmental support in areas including:

- Physical (*i.e.,* crawling and walking);
- Cognitive (*i.e.,* thinking and problem solving);
- Communication (*i.e.,* talking, listening, and understanding);
- Social/emotional (*i.e.,* playing and feeling secure); and
- Self-help (*i.e.,* eating and dressing).[109]

For example, through intervention services, a child with an IDD who has a speech delay will be able to interact with a speech therapist who identifies and implements strategies to overcome this delay.[110] In fact, specialized early intervention therapists help children with an IDD obtain, or improve upon, skills necessary for success throughout their entire life.[111] Additionally, early intervention staff focus on specific and effective intervention techniques, and they must partner with parents to support children with an IDD during their natural routines and activities.[112] Ultimately, incorporating the above services into the early lives of children with an IDD will positively impact their growth and development.[113] Additionally, as noted below, providing these services to children living with an IDD will provide a positive benefit to society as a whole.

B. THE ECONOMIC BENEFITS TO SOCIETY OF PROVIDING INTERVENTION SERVICES TO CHILDREN WITH AN IDD

Based upon an economic standpoint, investing in—and providing intervention and developmental disability services to—young children has an extremely high rate of, and excellent return on, investment.[114] Specifically, the economic argument can be summarized as follows: "[a return on investment] is generated from returns to the individual in terms of increased

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[108] DELMOLINO & HARRIS, *supra* note 2, at 22 (describing how applied behavior analysis treatment for children with ASD, "has the best ***empirically documented*** effectiveness in treating children aged 3 to 5 years who have a diagnosis of an autism spectrum disorder."); Orla Doyle et al., *Investing in Early Human Development: Timing and Economic Efficiency*, 3 ECON. AND HUM. BIOLOGY 1, 2 (2009), https://www ncbi nlm nih.gov/pmc/articles/PMC2929559/pdf/nihms224563.pdf ("Intervening in the zero-to-three period, when children are at their most receptive stage of development, has the potential to permanently alter their development trajectories and protect them against risk factors present in their early environment.").

[109] JACOB & SIKORA, *supra* note 29, at 103.

[110] *Id.* at 105.

[111] *Id.*

[112] *Id.*

[113] Doyle et al., *supra* note 108, at 2.

[114] *Id.* at 3 ("By investing early, the benefits are larger and are enjoyed for longer, which in turn increases the return to investment . . . the body of evidence . . . illustrates that there is a higher rate of return at younger ages for a constant level of investment.").

earnings, higher education, improved physical and mental well-being, and also through the positive externalities to society in terms of reduced crime and delinquency, public expenditure savings and increased tax revenues."[115] If society fails to provide children with an IDD with proper early intervention support, appropriate educational development, and necessary therapeutic resources, "[n]ot only will the costs to support these individuals all their lives be greater than those of a proper education, but society will lose out on the valuable contributions they could have made."[116]

However, to provide these developmentally essential—and economically beneficial—IDD services, governmental entities must provide adequate funding to the agencies that will implement these services.[117] Yet, it is costly for state and local governmental agencies to fund and provide these intervention services.[118] In fact, local school districts, which are mandated to provide a "free and appropriate education" to children with an IDD, often do not receive sufficient federal funding to provide this education, which results in "tension at the local level as special education encroaches on the general education budget."[119] Nevertheless, while it may be challenging to convince governmental agencies to allocate proper funding to support IDD specific services, broad public support exists for providing educational and intervention services to children with an IDD.[120] Therefore, on both an individual and societal basis, we must encourage government agencies to invest in intervention and developmental disability services.[121]

The next section will explore current federal and state-specific laws that address providing services to children with an IDD. Additionally, this section will highlight the State of North Dakota's current intellectual and developmental disability services legal framework. Finally, this segment will also identify other specific intellectual and developmental disability laws, which will form the framework for advocating for amending current North Dakota law.

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[115] *Id.*

[116] SICILE-KIRA, *supra* note 1, at 183.

[117] *Id.* at 184-85.

[118] Doyle, *supra* note 108, at 5 ("Interventions are costly to implement, therefore in order to derive the greatest benefits for children, while simultaneously having a high rate of return for investors, further research on the optimal time to intervene is needed.").

[119] SICILE-KIRA, *supra* note 1, at 185.

[120] 20 U.S.C. § 1400(c)(1) (highlighting a Congressional finding that "[i]mproving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.").

[121] SICILE-KIRA, *supra* note 1, at 183-88.

IV. CURRENT FEDERAL AND NORTH DAKOTA LAWS THAT ADDRESS CHALLENGES EXPERIENCED BY CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Both federal and state governments have enacted laws that provide protection and services to children with an IDD. However, these laws cover a wide variety of subject areas. The below listed paragraphs will highlight two of these areas, educational support and disability services.

A. APPLICABLE FEDERAL INTELLECTUAL AND DEVELOPMENTAL DISABILITY LAWS

The United States Congress has passed two important laws which provide services to children with an IDD: The Individuals with Disabilities Education Act and The Developmental Disabilities Assistance and Bill of Rights Act of 2000.[122]

1. The Individuals with Disabilities Education Act (IDEA)

In 1975, the United States Congress passed the Individuals with Disabilities Education Act (“IDEA”).[123] “The law was last reauthorized in 2004, and the [D]epartment [of Education] has periodically issued new or revised regulations to address the implementation and interpretation of the IDEA.”[124] In the IDEA, Congress explicitly made several important findings, including that:

> Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities[125] . . . . [T]he education of children with disabilities can be made more effective by . . . strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home;[126] . . . [and it is important to] provid[e] appropriate special education and related services, and aids and

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[122] 20 U.S.C. § 1400(a); Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. NO. 106-402, 114 STAT. 1677 (codified at 42 U.S.C. §§ 15001-15083).

[123] 20 U.S.C. § 1400(a); *see* Paul H. Lipkin et al., *The Individuals with Disabilities Education Act (IDEA) for Children with Special Educational Needs*, 136 AM. ACAD. OF PEDIATRICS e1650, e1651 (2015), https://publications.aap.org/pediatrics/article/136/6/e1650/33895/The-Individuals-With-Disabilities-Education-Act.

[124] *A History of the Individuals with Disabilities Education Act*, https://sites.ed.gov/idea/IDEA-History (Nov. 18, 2022).

[125] 20 U.S.C. § 1400(c)(1).

[126] 20 U.S.C. § 1400(c)(5)(B).

> supports in the regular classroom, to such children, whenever appropriate.[127]

The four "parts" of the IDEA are outlined in multiple statutes within Title 20, United States Code, Chapter 33—beginning at section 1400—and Title 34, Code of Federal Regulations, sections 300 and 303.[128] Most notably, the IDEA defines a "child with a disability" for children under three as a child, "with intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this chapter as 'emotional disturbance'), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities."[129]

Additionally, the IDEA defines an "at-risk infant or toddler" as a child "under 3 years of age who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual."[130] Finally, the IDEA describes that a "child with a disability" aged three through nine years specifically includes a child:

> (i) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in 1 or more of the following areas: physical development; cognitive development; communication development; social or emotional development; or adaptive development; and (ii) who, by reason thereof, needs special education and related services.[131]

One of the primary aims of the IDEA was to create a system for states to provide "early intervention" services to children with disabilities, developmental delays, or who are at high risk for experiencing developmental delays under the age of three years.[132] Additionally, of the "four parts" of the IDEA, the two most important are colloquially known as "IDEA Part C" and IDEA Part B."[133] Under the parameters of the IDEA Part

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[127] 20 U.S.C. § 1400(c)(5)(D).

[128] *See* 20 U.S.C. §§ 1400-1409 (Part A), 1411-1419 (Part B), 1431-1444 (Part C), 1450-1482 (Part D); 34 C.F.R. § 300 (Part B) and 34 C.F.R. § 303 (Part C).

[129] 20 U.S.C. § 1401(3)(A)(i).

[130] 20 U.S.C. § 1432(1).

[131] 20 U.S.C. § 1401(3)(B).

[132] 20 U.S.C. § 1400(c)(5)(F) (explaining that the law aims to provide "early intervening services to reduce the need to label children as disabled in order to address the learning and behavioral needs of such children"); 20 U.S.C. § 1400(d)(2) (stating that one of the purposes of the IDEA is "to assist States in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families"); 20 U.S.C. § 1431(a)(1); *see* DELMOLINO & HARRIS, *supra* note 2, at 53.

[133] *See* 20 U.S.C. §§ 1431-1444 (Part C) and 20 U.S.C. §§ 1411-1419 (Part B); 34 CFR § 303.13 (2022) (defining early intervention services); 34 C.F.R § 300.1 (2022) (explaining that the purpose of the regulation is to ensure "a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further

C, each state which chooses to accept the federal Part C funding is required to offer early intervention services to qualifying children under three years.[134] Under IDEA Part C, early intervention services are offered to children with disabilities or developmental delays in “(i) physical development; (ii) cognitive development; (iii) communication development; (iv) social or emotional development; or (v) adaptive development.”[135] Intervention services come in many different shapes and forms, but they may include services such as “speech-language pathology;” “physical therapy;” “occupational therapy;” “counseling,” and “home visits.”[136] IDEA Part C requires individual states to include “[a] rigorous definition of the term ‘developmental delay’ that will be used by the State in carrying out programs under this subchapter in order to appropriately identify infants and toddlers with disabilities that are in need of services under this subchapter.”[137] Moreover, each state is required to “[s]pecify the level of developmental delay in functioning or other comparable criteria that constitute a developmental delay in one or more of the developmental areas.”[138]

When children reach the age of three years, they transition from the early intervention services of IDEA Part C into the state educational system of IDEA Part B.[139] Under IDEA Part B, children aged three to twenty-one years with disabilities are guaranteed the right to “receive a free appropriate public education.”[140] During this time, children with a qualifying disability are

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education, employment, and independent living”); *see also* Lipkin et al., *supra* note 123 (“IDEA authorizes federal funding to states for EI [Early Intervention] services for infants and toddlers with disabilities and developmental delays (part C) and special education and related services for school-aged children with disabilities (part B) and relates principles for providing such services.”); *see also* DELMOLINO & HARRIS, *supra* note 2, at 53 (“Part C of this law concerns how states deliver services to children under the age of three years. When children reach three years of age, the responsibility for their services shifts to the state’s educational system, and those services are provided under Part B of IDEA.”).

[134] 20 U.S.C. § 1431(a)-(b) (“Congress finds that there is an urgent and substantial need . . . to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child’s first 3 years of life . . . . It is the policy of the United States to provide financial assistance to States.”); DELMOLINO & HARRIS, *supra* note 2, at 56; *see* SICILE-KIRA, *supra* note 1, at 184-85 (describing, in 2009, the federal government “covered 16.9 percent of the estimated excess cost of educating children with disabilities . . . . Obviously, funding is a major issue when it comes to providing for special education students.”).

[135] 20 U.S.C. § 1432(4)(C); 34 CFR § 303.13(a)(4).

[136] 20 U.S.C. § 1432(4)(E).

[137] 20 U.S.C. § 1435(a)(1); *see* 34 C.F.R. § 303.111 (2022).

[138] 34 C.F.R. § 303.111(b) (2022); *see* 34 C.F.R. § 303.21 (2022).

[139] *See* 20 U.S.C. § 1412(a)(9) (“Children participating in early intervention programs assisted under subchapter III, and who will participate in preschool programs assisted under this subchapter, experience a smooth and effective transition to those preschool programs.”); DELMOLINO & HARRIS, *supra* note 2, at 56-58.

[140] 20 U.S.C. § 1412(a)(1)(A) (“A free appropriate public education is available to all children with disabilities residing in the State between the ages of 3 and 21, inclusive, including children with disabilities who have been suspended or expelled from school.”); 20 U.S.C. § 1411(a)(1) (“The Secretary shall make grants to States . . . and provide funds to the Secretary of the

entitled to this free public education in the "least restrictive environment" so these children can receive an education in an environment "with children who are not disabled."[141] For example, under the IDEA, preschool aged children with developmental disabilities are eligible for special education services.[142] Thereafter, the child will remain in this program from ages three to five years until they transition into kindergarten.[143]

When children under three years of age with an IDD qualify for early intervention services under Part C of the IDEA, the child's parents and the child's service providers work together to create an Individualized Family Service Plan ("IFSP").[144] This plan includes both a section about the child's goals and objectives as well as the developmental services that will be provided to the child.[145] Each IFSP is different, but for a child experiencing speech delays, an IFSP may contain goals such as "asking verbally or through another communication system to use the toilet" and outline services offered to the child, including therapies from a "speech-language pathologist."[146] Thereafter, the child's service providers will regularly provide these Part C specific services to the child in the child and family's "natural environment," which is typically at the child's home or in the child's community setting.[147]

As stated above, once children with an IDD reach three years of age, they transition from Part C to Part B of the IDEA.[148] During this stage, children with an IDD progress from their individual or home settings, into the state's education system where a team of professionals develop an Individualized Education Program ("IEP").[149] An IEP is similar to an IFSP, but focuses solely on the child's needs, rather than on the needs of the child's

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Interior, to assist them to provide special education and related services to children with disabilities in accordance with this subchapter."); 20 U.S.C. § 1411(e)(3)(F)(i) ("Nothing in this paragraph shall be construed [] to limit or condition the right of a child with a disability who is assisted under this subchapter to receive a free appropriate public education.").

[141] 20 U.S.C. § 1412(a)(5)(A) ("To the maximum extent appropriate, children with disabilities . . . are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.").

[142] DELMOLINO & HARRIS, *supra* note 2, at 56 ("Under IDEA regulations, preschool-aged children with an ASD are eligible for special educational services. Different states use different terms to label young children who are eligible for preschool programs. The majority of states identify these children as having 'developmental delay' or 'significant developmental delay.'").

[143] *Id.* at 56-58.

[144] *Id.* at 55; *see* 20 U.S.C. § 1436 (outlining the contents and requirements of the IFSP).

[145] DELMOLINO & HARRIS, *supra* note 2, at 55.

[146] *Id.*

[147] *Id.* at 56.

[148] 20 U.S.C. § 1412(a)(9); Lipkin et al., *supra* note 123, at e1654.

[149] 20 U.S.C. § 1414(d) ("The term 'individualized education program' or 'IEP' means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section."); DELMOLINO & HARRIS, *supra* note 2, at 57.

family.[150] The IEP includes goals that the child's team would like the child to achieve in a school setting by evaluating the child's current level of performance as documented by specialized testing and observations.[151] For example, if a child is experiencing a developmental speech delay, the IEP may identify a goal of increasing more age appropriate speech.[152] In conjunction with this goal, the child's team may assign the child "three half-hour sessions with the speech-language pathologist every week to support her learning more advanced speech."[153]

2. The Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

The Developmental Disabilities Assistance and Bill of Rights Act ("DD Act") is "the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families."[154] In 2000, the United States Congress stated that the purpose of the Act was to "assure that individuals with developmental disabilities and their families . . . have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."[155] Additionally, Congress made the specific finding that "disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently . . . and to fully participate in and contribute to their communities through full integration and inclusion in . . . United States society."[156]

In "Plain Language," the DD Act created three programs to assist individuals with developmental disabilities.[157] First, it created University Centers for Excellence in Developmental Disabilities, with one located in each state, which study how to improve the lives of individuals with developmental disabilities.[158] Second, the DD Act created a DD Council for each state, which work with communities and schools to advance the lives of

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[150] DELMOLINO & HARRIS, *supra* note 2, at 57.

[151] *Id.*

[152] *Id.*

[153] *Id.*

[154] *Developmental Disabilities Act: What is the Developmental Disabilities Act?* ASS'N OF UNIV. CTRS. ON DISABILITIES, https://www.aucd.org/template/page.cfm?id=272 (last visited Nov. 21, 2022); *see* 42 U.S.C. § 15001(a).

[155] 42 U.S.C. § 15001(b).

[156] 42 U.S.C. § 15001(a)(1).

[157] *AUCD in Plain Language: What is the Developmental Disabilities Act?*, ASS'N OF UNIV. CTRS. ON DISABILITIES, https://www.aucd.org/docs/publications/DD%20Act%20Plain%20Language_EasyRead1.pdf, (last visited Nov. 21, 2022).

[158] *Id.*

people with disabilities.[159] Finally, the DD Act ensured that each state created an office of Protection and Advocacy, which intervene when individuals with disabilities are not treated fairly.[160]

Moreover, as noted *supra*, the DD Act enacted criteria for defining the term "developmental disability."[161] Specifically, the DD Act defines "developmental disability" as "a severe, chronic disability of an individual" traceable to "a mental or physical impairment" or combination thereof, which occurs before the age of twenty-two years, that will likely "continue indefinitely," "results in substantial functional limitations" in three or more enumerated life areas, and reflects an individual's need for specialized services and assistance.[162] The DD Act specifically enumerates seven major life areas: "(I) Self-care[;] (II) Receptive and expressive language[;] (III) Learning[;] (IV) Mobility[;] (V) Self-direction[;] (VI) Capacity for independent living[;] [and] (VII) Economic self-sufficiency."[163] As noted *infra*, the State of North Dakota has incorporated this criteria into its own developmental disabilities laws and eligibility criteria.

B. STATE OF NORTH DAKOTA DEVELOPMENTAL AND INTELLECTUAL DISABILITY LAWS

As noted in detail below, the State of North Dakota applies the IDEA and the DD Act through state laws enacted in the North Dakota Century Code and the North Dakota Administrative Code.[164] The North Dakota Department of Health and Human Services is responsible for administering the application of federal and state developmental disability laws to North Dakota residents who have an IDD condition.[165] Importantly, for North

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[159] *Id.*

[160] *Id.*

[161] *See supra* notes 38-39 and accompanying text.

[162] 42 U.S.C. § 15002(8)(A).

[163] *Id.*

[164] *See Section II: State Policies, Procedures, Methods and Descriptions*, N.D. DEP'T OF HUM. SERV. (Feb. 2013), https://www nd.gov/dhs/services/disabilities/earlyintervention/stateguidelines/ei-policies.pdf ("North Dakota ensures that any State rules, regulations, and policies relating to Part C conform to the purposes and requirements of Part C."); *see* Alvarez & Marsal, *supra* note 36, at 26 ("North Dakota currently uses the federal definition of developmental disability from the Developmental Disabilities Assistance and Bill of Rights Act of 2000 as part of determining eligibility for services.").

[165] *See Services and Help*, N.D. DEP'T OF HUM. SERV., https://www.nd.gov/dhs/services/ (last visited Nov. 21, 2022) (explaining that the North Dakota Department of Human Services offers services for: individuals with disabilities, autism, early childhood, and children and family); *see also Services to Individuals with Disabilities*, N.D. DEP'T OF HUM. SERV. https://www nd.gov/dhs/services/disabilities/index html (last visited Nov. 21, 2022) (documenting that the North Dakota Department of Human Services oversees the Developmental Disabilities Division and the Early Intervention Program.); *Section II: State Policies, Procedures, Methods and Descriptions*, *supra* note 164 ("The North Dakota Department of Human Services (ND DHS) is the Governor appointed lead agency for the Part C Early Intervention System since 1986."); *Burgum*

Dakota children with an IDD, the North Dakota Department of Health and Human Services oversees the North Dakota Early Intervention Program (IDEA Part C) and North Dakota Developmental Disabilities Division.[166] Additionally, the North Dakota Department of Public Instruction administers special education and related services for North Dakota children aged three to twenty-one years, while the North Dakota Department of Health and Human Services continues to provide developmental disability services (IDEA Part B).[167]

1. *The North Dakota Century Code*

The State of North Dakota has codified several laws which provide services and protections to intellectually and developmentally disabled children. North Dakota Century Code § 25-01.2-02 specifically asserts that "[a]ll individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting."[168] Furthermore, the North Dakota Century Code utilizes the definitions of the DD Act and defines the term "developmental disability" as:

> [A] severe, chronic disability of an individual which:
>
> a. Is attributable to a mental or physical impairment or combination of mental and physical impairments, including Down syndrome;
>
> b. Is manifested before the individual attains age twenty-two;
>
> c. Is likely to continue indefinitely;
>
> d. Results in substantial functional limitations in three or more of the following areas of major life activity:
>
> (1) Self-care;
>
> (2) Receptive and expressive language;
>
> (3) Learning;
>
> (4) Mobility;

Signs Bill Uniting Agencies Into the North Dakota Department of Health and Human Services (Apr. 28, 2021), https://www.governor.nd.gov/news/burgum-signs-bill-uniting-agencies-north-dakota-department-health-and-human-services ("Gov. Doug Burgum released the following statement today after signing House Bill 1247, which directs the state Department of Health and Department of Human Services to unite into the North Dakota Department of Health and Human Services, effective Sept. 1, 2022.").

[166] *See Services to Individuals with Disabilities*, *supra* note 165.

[167] *Understanding Early Childhood Transition: A Guide for Families and Professionals*, at 7, N.D. DEP'T OF HUM. SERV. (Mar. 2017), https://www nd.gov/dhs/services/disabilities/earlyintervention/stateguidelines/transition-guide.pdf.

[168] N.D. CENT. CODE § 25-01.2-02 (2022).

> (5) Self-direction;
>
> (6) Capacity for independent living; and
>
> (7) Economic sufficiency; and
>
> e. Reflects the individual's needs for a combination and sequence of special,interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.[169]

2. The North Dakota Administrative Code

Additionally, North Dakota offers services to children with developmental or intellectual disabilities through the "Intellectual Disabilities – Developmental Disabilities Program Management Services."[170] North Dakota, akin to IDEA Parts C and B, separates children with intellectual and disability eligibility service requirements into two separate groups, which are based upon a child's age.[171] For children aged zero to two years old, as stated in North Dakota Administrative Code section 75-04-06-04, North Dakota law codified expansive eligibility requirements.[172] However, for children aged three years old and older, as put forward in North Dakota Administrative Code section 75-04-06-02.1, North Dakota incorporated much more restrictive eligibility criteria.[173] The below listed paragraphs will compare these two North Dakota eligibility laws and evaluate their disparate application to children who have an IDD.

a. Children Aged Zero to Two Years Old

North Dakota has established both broad and liberal criteria to ensure that children under the age of three years obtain necessary developmental and intellectual disability services.[174] The practical effect is that North Dakota's liberal criteria and broad eligibility requirements serve as safeguards to children younger than three years old who are at risk for developing a developmental disability.[175] Specifically, pursuant to North Dakota Administrative Code section 75-04-06-04, children aged zero to two years

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[169] N.D. CENT. CODE § 25-01.2-01(3) (2022).

[170] N.D. ADMIN. CODE § 75-04-06 (2018).

[171] *Compare* N.D. ADMIN. CODE §§ 75-04-06-04 (creating a group for "Children birth through age two"), *with* 75-04-06-02.1 (2018) (creating a group for "Children age three and above").

[172] N.D. ADMIN. CODE § 75-04-06-04 (2018).

[173] N.D. ADMIN. CODE § 75-04-06-02.1 (2018).

[174] N.D. ADMIN. CODE § 75-04-06-04(1) (2018); *see* Alvarez & Marsal, *supra* note 36, at 14.

[175] Alvarez & Marsal, *supra* note 36, at 14; *see* SICILE-KIRA, *supra* note 1, at 194-95 ("Basically, every child under the age of three and at risk for developing a substantial disability if early interventions are not provided is eligible for early intervention.").

old are eligible for intellectual and developmental disability services if they have "a high-risk condition" or "a developmental delay."[176] Section 75-04-06-04(2)(b) defines "high-risk condition" as a child, "[w]ho, based on a diagnosed physical or mental condition, has a high probability of becoming developmentally delayed; or [w]ho, based on informed clinical opinion which is documented by qualitative evaluation information, has a high probability of developing a developmental delay."[177]

Moreover, section 75-04-06-04(2)(a) defines "developmental delay"—for children under the age of three years—as *either* a child who performs "twenty-five percent below age norms" in two enumerated areas *or* who performs "at fifty percent below age norms in one or more enumerated area."[178] Specifically, North Dakota evaluates the following conditions to determine whether a child performs "twenty-five percent below age norms:"

(a) cognitive development;

(b) gross motor development;

(c) fine motor development;

(d) sensory processing (hearing, vision, haptic);

(e) communication development (expressive or receptive);

(f) social or emotional development; or

(g) adaptive development[179]

Additionally, in conformity with federal law, North Dakota assesses the following factors to determine whether a child performs "at fifty percent below age norms:"

(a) cognitive development;

(b) physical development, including vision and hearing;

(c) communication development (expressive and receptive);

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[176] N.D. ADMIN. CODE § 75-04-06-04(1) (2018), The full text states:

> Service eligibility for children from birth through age two is based on distinct and separate criteria designed to enable preventive services to be delivered. Young children may have conditions which could result in substantial functional limitations if early and appropriate intervention is not provided. The collective professional judgment of the team must be exercised to determine whether the child has a high-risk condition or has a developmental delay, and if the child may need early intervention services. If a child, from birth through age two, has a high-risk condition or has a developmental delay, the child may be included on the caseload of an intellectual disabilities - developmental disabilities program manager and considered for those services designed to meet specific needs. Eligibility for continued service inclusion through intellectual disabilities - developmental disabilities program management must be redetermined by age three using criteria specified in section 75-04-06-02.1.

[177] N.D. ADMIN. CODE § 75-04-06-04(2)(b)(1)-(2) (2018).

[178] N.D. ADMIN. CODE § 75-04-06-04(2)(a)(1)-(2) (2018).

[179] N.D. ADMIN. CODE § 75-04-06-04(2)(a)(1)(a)-(g) (2018).

(d) social or emotional development; or

(e) adaptive development[180]

However, as noted below, once a child reaches their third birthday, the State of North Dakota applies a separate legal framework to determine if a child meets IDD eligibility requirements.

b. Children Aged Three Years and Above

Once a child turns three years old, in order to receive developmental disability services, that child must meet the criteria of one out of three strict eligibility categories.[181] Specifically, pursuant to North Dakota Administrative Code section 75-04-06-02.1, a child aged three years and over is eligible for intellectual disabilities - developmental disabilities program management services if the child has a:

"diagnosis of intellectual disability which is severe enough to constitute a developmental disability;"

"condition of intellectual disability . . . which is not severe enough to constitute a developmental disability, and the individual must be able to benefit from treatment and services purchased through the developmental disability division;" or

"condition, other than mental illness, severe enough to constitute a developmental disability, which results in impairment of general intellectual functioning or adaptive behavior similar to that of an individual with the condition of intellectual disability, and the individual must be able to benefit from services and intervention techniques which are so closely related to those applied to an individual with the condition of intellectual disability that provision is appropriate."[182]

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[180] N.D. ADMIN. CODE § 75-04-06-04(2)(a)(2)(a)-(e); *see also* 20 U.S.C. § 1401(3)(B)(i), 20 U.S.C. § 1432(4)(C); 34 C.F.R. § 303.13 (2022) (all evaluating the same set of factors as N.D. ADMIN. CODE § 75-04-06-04(2)(a)(2)).

[181] N.D. ADMIN. CODE § 75-04-06-02.1 (2018).

[182] N.D. ADMIN. CODE § 75-04-06-02.1(1)-(3) (2018). In addition to the above listed citation, subsection 1 requires:

> a. A diagnosis of the condition of intellectual disability must be made by an appropriately licensed professional using diagnostic criteria accepted by the American psychiatric association.
>
> b. Determination of whether the manifestation of the condition is severe enough to constitute a developmental disability must be done in accordance with the definition of developmental disability in North Dakota Century Code section 25-01.2-01.
>
> Additionally, subsection 3 requires "the application of professional judgment in a two-step process," namely,
>
> a. The team must first determine whether the condition is severe enough to constitute a developmental disability. North Dakota Century Code section 25-01.2-01 must be applied in order to determine if a developmental disability is present. The presence of a developmental disability does not establish eligibility for services through the intellectual disabilities - developmental disabilities program management services

For both subsections 1 and 3, the North Dakota Administrative Code § 75-04-06-02.1 requires that a determination be made about whether the person has a “developmental disability” as defined in North Dakota Century Code section 25-01.2-01.[183] As noted in Section IV(B)(1), *supra*, this statute requires that a developmental disability cause substantial functional limitations in three or more areas of major life activity.[184]

In summary, North Dakota operates two separate eligibility structures for children with an IDD based on the child’s age. When a child is aged zero to three-years old, North Dakota utilizes an eligibility structure that “braids” the IDEA Part C early intervention and developmental disability services criteria together into one single category.[185] However, once a child reaches their third birthday, North Dakota employs an eligibility structure which disconnects this single “braid” into two separate “pigtails”—namely special

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> system, but does require the team to consider all assessment data and apply professional judgment in the second step.
>
> b. The team must then determine whether services can be provided to an individual determined to have a condition, other than mental illness, severe enough to constitute a developmental disability. The team must have a thorough knowledge of the condition and service needs of the applicant, as well as a thorough knowledge of services that would be appropriate through the developmental disabilities system. When considering if intellectual disabilities - developmental disabilities program management is appropriate, the team must consider factors, including:
>
> (1) Whether the individual would meet criteria appropriately used to determine the need for services in an intermediate care facility for individuals with intellectual disabilities.
>
> (2) Whether appropriate services are available in the existing developmental disabilities service delivery system.
>
> (3) Whether a service, which uses intervention techniques designed to apply to an individual with intellectual disabilities, delivered by staff trained specifically in the field of intellectual disabilities, would benefit the individual.
>
> (4) Whether a service, designed for an individual with the condition of intellectual disability, could be furnished to the individual without any significant detriment to the individual or others receiving the service.
>
> c. If the team concludes, through the application of professional judgment, that an individual’s needs can be met through specific services purchased by the department for individuals who meet the criteria of subsection 1, an intellectual disabilities - developmental disabilities program manager may be assigned. Services may be provided, subject to the limits of legislative appropriation. New services need not be developed on behalf of the individual.

[183] *Id.*

[184] N.D. CENT. CODE § 25-01.2-01(3)(d) (2022) (These seven areas: “(1) Self-care; (2) Receptive and expressive language; (3) learning; (4) Mobility; (5) Self-direction; (6) Capacity for independent living; and (7) Economic sufficiency.”).

[185] Telephone Interview with Roxane Romanick, CEO, Designer Genes of N.D., Inc., (September 21, 2022) [hereinafter *Romanick Interview*] (Ms. Romanick provided me with this “braid” and “pigtail” analogy so that I could better articulate North Dakota’s developmental disability legal and administrative framework); *see* Letter from Roxane Romanick, CEO, Designer Genes of N.D., Inc , to Senate Human Services Committee, N.D. Senate, (Jan. 26, 2021) https://ndlegis.gov/prod/assembly/67-2021/testimony/SHUMSER-2256-20210126-3279-F-ROMANICK_ROXANE.pdf (requesting the North Dakota Senate Human Services Committee pass Senate Bill 2256 because “[t]he gap between our working eligibility processes for Developmental Disability services and our state definition of developmental disability is real. And it starts with children, the youngest of them being just shy of three years old”).

education services under IDEA Part B and developmental disability services—that each contain separate and distinct eligibility criteria.[186] The next subsection will provide additional information about the North Dakota Early Intervention Program, North Dakota Early Childhood Special Education Services, and North Dakota Developmental Disability Services.

C. THE STATE OF NORTH DAKOTA EARLY INTERVENTION PROGRAM, NORTH DAKOTA EARLY CHILDHOOD SPECIAL EDUCATION SERVICES PROGRAMS, AND NORTH DAKOTA DEVELOPMENTAL DISABILITY SERVICES PROGRAMS

1. The North Dakota Early Intervention Program

The North Dakota Early Intervention Program applies the eligibility requirements contained within North Dakota Administrative Code section 75-04-06-04(2)(a) to children under three years of age.[187] Moreover, the North Dakota Early Intervention Program operates in conformity with the federal requirements of IDEA Part C. Specifically, as contained within the State of North Dakota's Policies, Procedures, Methods and Descriptions for Part C of the IDEA ("Part C Policies") "North Dakota has in effect a statewide system of early intervention services that meets the requirements of section 635 of IDEA, including policies and procedures that address, at a minimum, the components required in [34 C.F.R.] §303.111 through §303.126."[188]

Further, North Dakota's Part C Policies recognize that state laws conform to Part C of the IDEA that all "infants and toddlers with disabilities" shall receive appropriate early intervention services, and all "infants and toddlers with disabilities" shall complete an IFSP with their family and the state.[189] After a North Dakota child enrolls in the Early Intervention Program, they are entitled to the services outlined in IDEA Part C to meet their individual developmental needs including, speech and language pathologists, psychologists, special educators, and physical therapists.[190] These specialized services help ensure that North Dakota infants and toddlers with disabilities or developmental delays achieve their full potential.[191]

When North Dakota children approach their third birthday, the Part C Policies outline a transition plan that takes appropriate "[s]teps for the toddler

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[186] *Romanick Interview*, *supra* note 185.

[187] *See Section II: State Policies, Procedures, Methods and Descriptions*, *supra* note 164, at 13 (defining "Developmental Delay" according to the criteria listed in N.D. ADMIN. CODE § 75-04-06-04(2)).

[188] *Id.* at 1.

[189] *Id.* at 2.

[190] *Id.* at 18-19.

[191] *See id.*

with a disability and his or her family to exit from the Part C program."[192] During this review, the North Dakota Department of Human Services ensures the state reviews the IDEA Part B program, early childhood special education, options available to "all toddlers with disabilities" with the children's family and that it provides "[a]ny transition services that the IFSP Team identifies as needed by that toddler and his or her family."[193] If a North Dakota child with an IDD qualifies for IDEA Part B, on the date of the child's third birthday, they will transition to the state's special educational system.[194]

2. *North Dakota Early Childhood Special Education Services*

In accordance with IDEA Part B, the North Dakota Department of Public Instruction administers special education, and related services, to children with disabilities aged three to twenty-one years old. [195] The school district where the child's family home is located provides these special educational services to the child.[196] In North Dakota, children are eligible for early childhood special education services if, after appropriate evaluation, they meet criteria outlined in the IDEA, notably, "intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance . . . orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities."[197] Finally, younger children may be eligible if they meet the criteria for a "Non-Categorical Delay," which is appropriate "when a disability is not clearly identified, but delays are evident."[198]

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[192] *Id.* at 9.

[193] *Id.*; *see* 34 C.F.R. § 303.344(h) (2022) (explaining that the IFSP transition plan should include the steps and services needed to make a smooth transition from IDEA Part C to "[p]reschool services under part B of the Act, to the extent that those services are appropriate").

[194] *See Section II: State Policies, Procedures, Methods and Descriptions*, *supra* note 164, at 9; 34 C.F.R. § 303.344(h) (2022).

[195] *Understanding Early Childhood Transition: A Guide for Families and Professionals*, *supra* note 167, at 7.

[196] *Id.*

[197] 20 U.S.C. § 1401(3)(A)(i); *Understanding Early Childhood Transition: A Guide for Families and Professionals*, *supra* note 167, at 7-8.

[198] *Understanding Early Childhood Transition: A Guide for Families and Professionals*, *supra* note 167, at 8; *see Guidelines: Identification and Evaluation of Students with Non-Categorical Delay for Ages 3 through 9*, at 5, N.D. DEP'T OF PUB. INSTRUCTION (Mar. 2007), http://www.library.nd.gov/statedocs/PublicInstruction/NCDguidelines20071128.pdf (explaining that the non-categorical delay eligibility requirements as:

> Eligibility based on developmental delay or inconsistencies in demonstrating developmental milestones. Developmental delay is defined as demonstrating a developmental profile that documents skill acquisition that is significantly below that of chronologically same-age peers in one or more of the following areas: 1) cognitive; 2) fine motor; 3) motor; 4) vision; 5) hearing; 6) communication, which may include speech and language; 7) preacademic; 8) socialization, which may include interactional and emotional development; and 9) adaptive skills which may include self-help,

If a child with an IDD meets the IDEA Part B criteria for early childhood special education services, the child, their parents, and local education agency actors will meet to formulate an IEP, which outlines the child's performance goals in the education setting.[199] Thereafter, the local education agency will put the child's IEP into action by: 1) preparing the child for the new education setting and programs; 2) providing the child with appropriate classroom instruction; and 3) offering the child developmental or remedial therapies and services.[200] The school district will conduct an annual review of the IEP and—before the child turns six years old—the school district shall reevaluate the child to ensure that they are still eligible to receive special education services.[201]

3. *North Dakota Developmental Disabilities Services*

The North Dakota Developmental Disabilities Division "provides support and training to clients and families in order to maximize community and family inclusion, independence, and self-sufficiency."[202] Moreover, the Disabilities Division "contracts with private, nonprofit, and for-profit organizations to provide an array of residential services, day services, and family support services."[203] Specifically, North Dakota residents with disabilities, who meet certain criteria, are eligible for two important services, "The Traditional Individuals Intellectual Disabilities/Developmental Disability Home and Community-Based Services Waiver" ("DD Waiver") and Medicaid State Plan services.[204]

The DD Waiver provides "an array of services that allow eligible clients of all ages the opportunity to receive home-and community-based alternatives to institutional placement" while the Medicaid State Plan "provides traditional medical services such as physician services, lab, hospital, dental, occupational therapy, physical therapy, speech therapy, home health care, etc."[205] Finally, North Dakota residents with a disability are eligible to obtain the support of a Developmental Disabilities Program Manager ("DDPM") whose primary responsibility is to "provide assistance

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attending, behavior control, and creative play; exhibited by a child, 3 through 9 years of age, who is determined by a multi-disciplinary assessment team to be in need of special education.).

[199] *Understanding Early Childhood Transition: A Guide for Families and Professionals*, *supra* note 167, at 27.

[200] *See id.* at 35-37.

[201] *Id.* at 36-37.

[202] *Provider Manual*, at 4, N.D. DEP'T HUM. SERV. (May 2022), https://www nd.gov/dhs/services/disabilities/docs/dd-provider-manual.pdf.

[203] *Id.*

[204] *Id.*

[205] *Id.*

and support to individuals with an intellectual or developmental disability, or a related condition."[206] However, "[t]he criteria used to determine eligibility for IID/DD Medicaid services and IID/DD Program Management services are different [,and][a]n individual may be eligible for IID/DD Program Management per North Dakota Administrative Code (NDAC) 75-04-06 but may not meet the criteria for services covered by Medicaid."[207] In summary, if a child is found eligible for Development Disability Services, they are able to elect among available Developmental Disability Services, including Developmental Disability providers.[208] These services include in-home supports (including respite care), equipment and supplies, home modifications, and program management.[209]

The North Dakota Developmental Disabilities Services applies the eligibility criteria, listed in subsection IV(B)(2)(i) above, to children under three years of age, and the criteria in subsection IV(B)(2)(ii) to children aged three years and above. Specifically, for children aged zero to two years old, Disabilities Services applies the more liberal criteria codified in North Dakota Administrative Code section 75-04-06-04 and, for children aged three and above, applies the more stringent criteria codified in North Dakota Administrative Code section 75-04-06-02.1 and North Dakota Century Code section 25-01.2-01, which requires a diagnosis of either an intellectual or developmental disability.[210]

Additionally, each applicable waiver that North Dakota offers has separate requirements and is subject to funding limitations.[211] For example, for the DD Waiver, the number of individuals served under this waiver is "limited to the capacity specified in the federally approved [DD Waiver]."[212] Specifically, "[e]ligible clients will be enrolled in the [DD Waiver] on a first-come, first-served basis until the [DD Waiver] capacity is reached, excluding any reserved slots [,and] [w]hen the enrollment capacity has been reached, the DD Division will keep a waiting list based on the date of application."[213] Additionally, for the Medicaid State Plan "[t]he Human Service Zone local office determines financial eligibility for Medicaid Health Care Coverage

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[206] *Id.* at 5.

[207] *Id.*

[208] *Process to Obtain Developmental Disabilities Program Management (DDPM) and DD Services*, at 1, N.D. DEP'T OF HUM. SERV. (June 21, 2021), https://www nd.gov/dhs/services/disabilities/docs/dd-eligibility-determination-process.pdf.

[209] *Provider Manual*, *supra* note 202, at 9, 59.

[210] *Provider Manual*, *supra* note 202, at 5-6.

[211] *Id.* at 6-8.

[212] *Id.* at 7.

[213] *Id.*

[which depends] on . . . for children, on their parent(s) or legal decision maker's income."[214]

North Dakota offers Medicaid to disabled individuals who meet certain criteria.[215] This eligibility comes in the form of a waiver.[216] The State of North Dakota currently provides five separate waivers that serve North Dakota children, namely: 1) Intellectual/Developmental Disability; 2) Autism Spectrum Disorder;[217] 3) Medically Fragile children; 4) Children's Hospice; and 5) North Dakota Medicaid 1915(i) Home and Community based Behavioral Health Services.[218] As noted above, a wait list exists for certain waivers, including the Autism Spectrum Disorder and Medically Fragile children waivers. As of June 2022, there were 58 North Dakota children on the Autism Spectrum Disorder Waiver waitlist and 9 children on the Medically Fragile Waiver waitlist.[219] Recently, the State of North Dakota created the Autism Services Voucher Program, which is separate from the Autism Spectrum Waiver, and "provides voucher funds up to $7,500 per year to help families with the cost of supporting a child with autism."[220]

The next section of this article will review and explore a recent study regarding North Dakota's Developmental Disabilities and Autism Spectrum Disorder Programs. This study identifies and highlights gaps existing within North Dakota's developmental disability laws, which limit North Dakota children with an IDD from obtaining access to developmental disability services. The author will note some of this study's important facts and conclusions, which provide a roadmap for instituting pragmatic changes to these laws. Thereafter, the author will advocate for a proposal to modify existing North Dakota developmental disability laws to ensure that children with an IDD condition or conditions, specifically those aged three to six years old, receive adequate developmental disability services.

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[214] *Id.* at 8.

[215] N.D. ADMIN. CODE § 75-03-23-04 (2009).

[216] *Id.*

[217] N.D. ADMIN. CODE § 75-03-39-02 (2022) (outlining a child's "[e]ligibility for services under the Medicaid autism spectrum disorder birth through fifteen waiver").

[218] Alvarez & Marsal, *supra* note 36, at 11-12 (providing application forms for the five above listed waivers).

[219] *Id.* at 42 (showing the current waitlist for the autism spectrum disorder waiver is 58 people and the Medically Fragile Waiver is 9 people); *Provider Manual*, *supra* note 202, at 7.

[220] *Autism Services Voucher Program: Serving Children Ages Three Through 17*, N.D. DEP'T OF HUM. SERV. (Jan. 2022), https://www nd.gov/dhs/autism/docs/dn-345-autism-voucher-brochure.pdf; *see Department of Human Services - Autism Services*, https://www nd.gov/dhs/autism/ (last visited Nov. 23, 2022).

V. A PROPOSAL FOR AMENDING CURRENT NORTH DAKOTA DEVELOPMENTAL DISABILITY LAWS TO EXPAND ELIGIBILITY CRITERIA

A significant percentage of students in the United States require special education and disability services.[221] Moreover, across the country, "students with disabilities are more than twice as likely to be suspended as those without disabilities, and the loss of instructional time increases the risk of academic failure and school aversion."[222] For the 2013-2014 school year, 12.2% of nationwide public-school students received special education services.[223] During this same period, the State of North Dakota had a similar percentage of public-school students, namely 12.4%, who received special education services.[224] In 2015-2016, in North Dakota, 4,242 children were identified with a specific learning disability, which comprised 35.4% of the thirteen disability categories contained within special education law.[225] Additionally, of the children included in the remaining 64.6% of the twelve disability categories, 6.1% of children were identified with intellectual disabilities, 7.8% with autism spectrum disorder, and 8.6% with a developmental delay.[226] Therefore, North Dakota has a considerable population of children who require special education and developmental disability services. The forthcoming subsections will highlight the gaps in North Dakota law, which limit children with an IDD's access to disability services and will provide a framework for amending North Dakota law to remove these gaps.

A. THE ALVAREZ & MARSAL STUDY: GAP ANALYSIS, FINDINGS, AND RECOMMENDATIONS

1. The North Dakota Legislative Council's Funding of this Study

In October 2021, after the enactment of Senate Bill 2256 in the Sixty-Seventh Legislative Assembly of North Dakota, the North Dakota Legislative Council obtained funding to study the North Dakota Developmental Disabilities and Autism Spectrum Disorder programs.[227] One of the primary

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[221] *The State of Learning Disabilities: Understanding the 1 in 5*: *North Dakota State Snapshot*, NAT'L CTR. FOR LEARNING DISABILITIES (2017), https://www.ncld.org/wp-content/uploads/2017/03/North-Dakota.Snapshot.v2.pdf.

[222] *Id.*

[223] *Id.*

[224] *Id.*

[225] *Id.*

[226] *Id.*

[227] *See generally Information Regarding the Request for Proposal and Proposal Responses – Study of Developmental Disabilities Services and Autism Spectrum Disorder Programs*, N.D. LEGIS. COUNCIL (Oct. 2021), https://www.ndlegis.gov/files/resource/committee-

goals in funding this study was to "identify potential pathways for individuals who have a developmental disability and individuals who have an autism spectrum disorder but do not meet the eligibility criteria for existing programs."[228] Alvarez & Marsal Holdings, LLC, ("Alvarez & Marsal") received a contract to conduct a study on, and issue a report about, the developmental disabilities and autism spectrum disorder programs.[229] Thereafter, on June 30, 2022, Alvarez & Marsal provided a 120 page presentation entitled North Dakota Developmental Disabilities Study: Report & Oral Presentation ("Study") to the Human Services Committee of the North Dakota Legislative Branch pertaining to the "Developmental Disabilities Services and Autism Spectrum Disorder Programs."[230]

2. *The Study's Gap Analysis*

In this Study, Alvarez & Marsal conducted a "Gap Analysis" which identified existing gaps in access to North Dakota disability services. [231] In particular, this Study analyzed the available avenues to obtain North Dakota disability services, compared these service avenues to similarly situated states, and thereafter—to close these gaps—highlighted possible approaches to modify or expand North Dakota disability programs.[232] As part of this "Gap Analysis," the Study interviewed North Dakota state employees (including Developmental Disabilities Program Managers), interviewed advocates (including family members), and conducted listening sessions with

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memorandum/23.9165.01000.pdf; S. B. 2256, 67 Leg. Assemb., Reg. Sess. (N.D. 2021) (explaining that his bill would "provide for a legislative management study of the state's developmental disability services and autism spectrum disorder waiver and voucher programs").

[228] *Information Regarding the Request for Proposal and Proposal Responses – Study of Developmental Disabilities Services and Autism Spectrum Disorder Programs*, *supra* note 227, at 1.

[229] *Id.* Specifically, the State of North Dakota contracted Alvarez & Marsal to:

> [1.] Gather information from key individuals within the Department of Human Services, including staff responsible for the administration of developmental disabilities programs and staff responsible for key functions in the programs.
>
> [2.] Gather information from other key stakeholders, including legislators, representatives of organizations that advocate for developmental disabilities services, members of the Autism Spectrum Disorder Task Force, members of other task forces and councils that relate to developmental disabilities, and self-advocates and families of individuals receiving developmental disability or autism spectrum disorder services.
>
> [3.] Gather and analyze data from the Department of Human Services regarding waiver applications, budget information, needs assessments, program and service access, assessment tools, eligibility determinations, and program utilization.
>
> [4.] Research other states to compare program services in peer states and to review planning and implementation approaches in other states.

[230] *Tentative Agenda, Human Services Committee*, N.D. LEGIS. MGMT. (June 30, 2022), https://ndlegis.gov/assembly/67-2021/interim/23-5168-02000-meeting-agenda.pdf; Alvarez & Marsal, *supra* note 36, at 1.

[231] Alvarez & Marsal, *supra* note 36, at 3-4.

[232] *Id.* at 4.

Autism Spectrum Disorder Taskforces, Autism Spectrum Disorder Advocacy Coalitions, and special education teachers and administrators.[233] Furthermore, the Study reviewed a large volume of documents from the North Dakota Department of Health and Human Services and examined the following North Dakota services, including:

- Aging;
- Autism Spectrum Disorder Voucher;
- Behavioral Health;
- Early Childhood;
- Early Intervention;
- Early & Periodic Screening, Detection, & Treatment;
- Home & Community-Based Services Waivers;
- Medicaid State Plan; Specialized Health Services; and
- Vocational Rehabilitation.[234]

Additionally, in this Study, Alvarez & Marsal conducted a national scan to pinpoint “promising practice states,” which included reviewing information from neighboring states, such as Minnesota, South Dakota, and Montana, as well as non-neighboring states, including New York, New Hampshire, Iowa, and Wisconsin.[235] Moreover, the Study summarized existing disability services available to North Dakota residents, notably available North Dakota Home and Community-Based Services (“HCBS”) and DD Waivers.[236] Specifically, the Study examined North Dakota’s available HCBS Waivers, which “meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.”[237] As noted above, HCBS Waivers provide “an array of services that allow eligible clients of all ages the opportunity to receive home-and community-based alternatives to institutional placement.”[238]

Alvarez & Marsal summarized additional information about HCBS Waivers, including that: Medicaid serves as the primary funder of HCBS Waivers; individual states establish HCBS Waivers to provide long-term services to disabled individuals in their homes, rather than an institutional setting; and the services states provided through HCBS can include in-home support and respite services.[239] Generally, to obtain HCBS Waiver services, individuals must satisfy the need for a Level of Care (“LOC”), which meet

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[233] *Id.*
[234] *Id.*
[235] *Id.* at 6.
[236] *Id.* at 7, 11.
[237] *Id.* at 7, 12.
[238] *Provider Manual*, *supra* note 202, at 4.
[239] Alvarez & Marsal, *supra* note 36, at. 7.

an individual state's eligibility standards for services in an institutional setting.[240] HCBS Waivers apply to a class of people in need of Long Term Services & Support ("LTSS"), including, as pertinent for this article, individuals with an IDD.[241] The objective of state LOC determinations is "to ensure that the right people are getting the right amount of care, in the right environment," including those individuals who have the greatest need for LTSS.[242]

Alvarez & Marsal's Study identified five separate waivers, for which the State of North Dakota provides HCBS services, namely: 1) Intellectual and Developmental Disability ("ID/DD"); 2) Autism Spectrum Disorder; 3) Medically Fragile; 4) Children's Hospice; and 5) North Dakota Medicaid 1915(i) Home and Community based Behavioral Health Services.[243] The ID/DD Waiver provides individuals with an IDD access to numerous services—for example, in-home support—across their lifespan.[244] The Autism Spectrum Disorder Waiver provides children with autism, from birth to fifteen years, with access to respite, service management, and assistive technology services.[245] The Medically Fragile Waiver provides services—for example supplies, in-home support, and counseling—to children from the age of three through seventeen, "who require medications, treatments, and other specialized care due to illness or congenital disorders."[246] The Children's Hospice Waiver provides hospice services to children from birth to twenty-one years, who require palliative care."[247] Finally, the North Dakota Medicaid 1915(i) Home and Community based Behavioral Health Services offers individuals, of all ages, access to "Home and Community-based Behavioral Health Services."[248] For purposes of this article, the author will focus on three of these waivers as they apply to children: 1) the ID/DD Waiver; 2) the Autism-Spectrum Disorder Waiver; and 3) the Medically Fragile Waiver. The next section will highlight Alvarez & Marsal's findings pertaining to North Dakota's application of these waivers to North Dakota children.

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[240] *Id.* at 8.

[241] *Id.*

[242] *Id.*

[243] *Id.* at 11-12.

[244] *Id.* at 11.

[245] *Id.*

[246] *Id.*

[247] *Id.* at 12.

[248] *Id.*

3. *The Study’s Findings*

After reviewing the State of North Dakota’s disability services, Alvarez & Marsal’s Study made several important findings.[249] Of significance, the Study outlined that “North Dakota’s Strengths” were 1) the ID/DD Waiver program, which “provides comprehensive supports to individuals throughout their lifespan;” 2) hard-working “State Staff” who have “have a demonstrated commitment to caring for individuals with disabilities;” and 3) “a strong network of [community] advocates who are passionate about providing the best services for individuals with disabilities.”[250] Moreover, the Study found that North Dakota’s ID/DD Waiver offers “generous services to kids under three and delivers these supports in a highly cost-effective manner,” articulated how “[e]vidence supports that investments in children at this earliest age group provide the most benefit,” and explained waiver eligibility offers “access to Medicaid state plan services.”[251]

However, the Study also identified a concerning trend occurring when children turn three years old; specifically, that “91% of waiver participants who turned three during the 2018-2021 sample period did not continue beyond their third birthday.”[252] This “drop-off” has several practical, negative effects on children and their family, including that—on their third birthday—children who “do not yet have access to additional school support” lose access, not only to the ID/DD Waiver, but also to Medicaid insurance.[253] Notably, the Study highlighted how North Dakota’s HCBS Waivers all have different eligibility requirements and fluctuating funding support which creates “disparate access to services” specifically for the Autism Spectrum Disorder Waiver, which ends at age fifteen, and the ID/DD Waiver, which has LOC changes at age three.[254] In particular, the Study noted, while the ID/DD Waiver does not have a waitlist for access to services, both the Autism Spectrum Disorder and Medically Fragile Waivers had substantial wait lists.[255] The practical effect of these waitlists is that North Dakota children who otherwise meet the eligibility criteria for both waivers do not receive services immediately, but instead must wait their place in the waitlist

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[249] *Id.* at 13-16.

[250] *Id.* at 13.

[251] *Id.* at 14.

[252] *Id.* at 15 (articulating this drop off occurred due to a “mix of denials and families who chose not to continue services”).

[253] *Id.*

[254] *Id.* at 16.

[255] *Id.* at 16, 42 (noting at the time of the Study’s completion, the Autism Spectrum Disorder Waiver had 58 children and the Medically Fragile Waiver had 9 children on their respective waitlists).

queue.[256] Based upon these disparities, the Study made several important recommendations, which are discussed in the next subsection.

4. The Study's Recommendations

Alvarez & Marsal's Study recommended to "fill the gap for [North Dakotans] with developmental disabilities" to obtain access to services under the ID/DD, Autism Spectrum Disorder, and Medically Fragile Waivers.[257]

First, the Study recommended North Dakota should modernize its definition of "developmental disabilities" from the federal DD Act, which "aligns major life activities with adaptive deficits that are conceptual" to "requiring significant functional limitations in two of the following three areas of adaptive functioning: conceptual, social, and practical."[258] The Study articulated three of North Dakota's peer states, Iowa, Kansas, and South Dakota, already "use all three categories of adaptive deficits."[259]

Second, the Study recommended North Dakota implement a "cross-disability children's Waiver . . . to provide services for children with support needs, regardless of disability category."[260] This "cross-disability" program would fill gaps in North Dakota's current disability services programs by ensuring children with disabilities receive much needed disability services.[261] Specifically related to children, the Study recommended: 1) children under three years of age be covered by one single comprehensive waiver; 2) after a reassessment, children three to six years of age be served under a comprehensive IDD and ASD Waiver; and after a "transition point" and LOC reassessment, 3) children aged six years and above, "with intellectual disabilities, developmental disabilities, autism, and those that are medically fragile," be served under a "Cross Disability Individual and Family Support waiver."[262] The proposed "comprehensive waiver" for IDD and ASD would eliminate a waitlist.[263]

In the forthcoming section, the author will incorporate the findings and recommendations of Alvarez & Marsal's Study to create a proposal for expanding services to North Dakota children with an IDD.

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[256] *Id.* at 40.

[257] *Id.* at 24.

[258] *Id.* at 26; *but cf.* N.D. CENT. CODE § 25-01.2-01(3)(d) (requiring that a "developmental disability" cause "substantial functional limitations in three or more of the following areas of major life activity: (1) Self-care; (2) Receptive and expressive language; (3) Learning; (4) Mobility; (5) Self-direction; (6) Capacity for independent living; and (7) Economic sufficiency.").

[259] Alvarez & Marsal, *supra* note 36, at 26.

[260] *Id.* at 29.

[261] *Id.* at 30, 33-34.

[262] *Id.* at 32-33.

[263] *Id.* at 34. (estimating that by creating this cross-disability waiver that the waitlist capacity can be expanded to such an extent that every child who meets eligibility criteria will receive services).

B. A PROPOSAL FOR EXPANDING NORTH DAKOTA SPECIAL EDUCATION AND DEVELOPMENTAL DISABILITY SERVICES FOR CHILDREN WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

As highlighted by Alvarez & Marsal’s Study, North Dakota is in a unique position to identify and fill gaps in access to North Dakota disability services related to children with an IDD.[264] To fill these gaps, the State of North Dakota should incorporate several recommendations of this Study by expanding eligibility criteria for IDD special education, increasing access to IDD HCBS Waivers, and removing waitlists from the State’s HCBS Waivers. However, to accomplish these goals, North Dakota will have to increase expenditures to fund these services. Nevertheless, funding expenditures that benefit children with an IDD and their families, will ultimately provide an exponential future benefit to the State of North Dakota.[265] Additionally, the Alvarez & Marsal Study also concluded that expanding North Dakota disability services will have a long-term positive impact on both individuals and society.[266] Therefore, expanding services to children with an IDD is beneficial from both a charitable and economic perspective. In the below listed sub-sections, the author will outline his proposed amendments to North Dakota law to expand services to children with an IDD.

1. Expanding Special Education Access and Creating New Developmental Disability Services Criteria for North Dakota Children Aged Three to Six Years Old

For children aged three to six years old, North Dakota should both expand special education access and create new developmental disability services eligibility criteria. As noted above, providing early intervention services to children from birth to their third birthday significantly benefits children with an IDD.[267] However, under North Dakota’s current ID/DD Waiver program, scores of children who turn three years old with an IDD or an IDD condition do not continue to receive necessary developmental services, with “91% of waiver participants who turned three during the 2018-

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[264] *Id.* at 3-4.

[265] Doyle et al., *supra* note 108, at 4 (“By investing early, the benefits are larger and are enjoyed for longer, which in turn increases the return to investment . . . . [T]he body of evidence . . . illustrates that there is a higher rate of return at younger ages for a constant level of investment.”).

[266] Alvarez & Marsal, *supra* note 36, at 35-36.
(“[T]here are people with disabilities now who are in correctional facilities, homeless shelters, and foster care; or who have declared bankruptcy due to medical debt [and] [a] strong HCBS program will help mitigate those costs.”).

[267] DELMOLINO & HARRIS, *supra* note 2, at 24-27, 66-67, 76-77, 106-07; JACOB & SIKORA, *supra* note 29, at 103-06.

2021 sample period [] not continu[ing] beyond their third birthday."[268] Therefore, expanding special education access and creating new developmental disability services eligibility criteria for children aged three to six years will allow these children greater access to special education and developmental disability services during their most developmentally important years. Although North Dakota operates separate special education and developmental disability services programs—since, from a parent's perspective, these programs are often intertwined—the author recommends the State of North Dakota provide more alignment and coordination between these programs to support families who are navigating these two processes.

a. Special Education Services for Children Aged Three to Six

i. Expanded Eligibility Criteria

North Dakota should expand eligibility criteria for special education services for children aged three to six years old. As stated above, once a North Dakota child aged zero to two years enrolls in the Early Intervention Program, they are entitled to the services outlined in IDEA Part C to meet their individual developmental needs including speech and language pathologists, psychologists, special educators, and physical therapists.[269] Additionally, North Dakota follows IDEA Part B by offering early childhood special education services to children aged three and above with "intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance . . . , orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities."[270] However, it is difficult to diagnose certain IDD conditions in children aged between three and six years, particularly autism spectrum disorder.[271]

Therefore, it is necessary to expand special education access to promote greater inclusion of children aged three to six years who may have an IDD or developmental delay. The author recommends utilizing the "Non-Categorical Delay" category, which is appropriate "when a disability is not clearly identified, but delays are evident," to a greater extent for children aged three to six years who may have an IDD or IDD condition.[272] Specifically, the "Non-Categorical Delay" category should be utilized to a greater extent to

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[268] Alvarez & Marsal, *supra* note 36, at 15.

[269] *Section II: State Policies, Procedures, Methods and Descriptions*, *supra* note 164, at 18-19, 21-22.

[270] 20 U.S.C. § 1401(3)(A)(i); *Understanding Early Childhood Transition: A Guide for Families and Professionals*, *supra* note 167, at 7-8.

[271] *See* SICILE-KIRA, *supra* note 1, at 21.

[272] *Understanding Early Childhood Transition: A Guide for Families and Professionals*, *supra* note 167, at 8.

grant special education access to children with an IDD or IDD condition who do not fall into any other recognized category but have “skill acquisition that is significantly below that of chronologically same-age peers.”[273] Finally, North Dakota should enact procedures that provide better alignment between North Dakota’s special education and developmental disabilities services programs for child evaluation and testing processes. When a child with an IDD turns three-years old, the State of North Dakota utilizes separate legal criteria to evaluate if the child is eligible for special education services, developmental disability services, or services under both programs. Even though these two programs employ different eligibility criteria, parents may question why their child is being submitted to multiple periods of testing and evaluation. As a result, North Dakota should implement procedures which provide greater cooperation between special education and developmental disability programs relating to the evaluation and testing of a child with an IDD.

ii. Universal Preschool

Additionally, the author recommends North Dakota institute a statewide universal preschool. Currently, North Dakota children aged three to five years old who may have an IDD lose access to additional school support if they do not qualify for special education.[274] If North Dakota enacted universal preschool for all North Dakota children, the state would see two benefits by enhancing education for all children while also ensuring children with an IDD receive school support. In the United States, during the 2018-2019 school year, “[s]tate-funded preschool served 1,629,804 children” with 85% of these children aged four years old.[275] During this school year, “34% of 4-year-olds and 5.9% of 3-year-olds” in the United States participated in state-funded preschool.[276]

Universal preschool programs provide long-term benefits to both the children they educate and to society as a whole.[277] Specifically, studies have shown that “public preschool enrollment boosts post-secondary and college preparatory outcomes . . . [and creates] fewer disciplinary incidents in high

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[273] *See Guidelines: Identification and Evaluation of Students with Non-Categorical Delay for Ages 3 through 9*, *supra* note 198, at 5.

[274] Alvarez & Marsal, *supra* note 36, at 15.

[275] Allison H. Friedman-Krauss et al., *The State of Preschool 2019*, at 14, NAT’L INST. FOR EARLY EDUC. RSCH. (2020), https://nieer.org/wp-content/uploads/2020/11/YB2019_Full_Report.pdf.

[276] *Id.*

[277] Guthrie Gray-Lobe et al., *The Long-Term Effects of Universal Preschool in Boston*, at 21 NAT’L BUREAU OF ECON. RSCH. (2021), https://www nber.org/system/files/working_papers/w28756/w28756.pdf (“High-quality preschool programs have the potential to produce lasting impacts on skills and improve long-term outcomes for disadvantaged students.”).

school."[278] Additionally, the findings of at least one recent study illustrate "the potential for a universal preschool program to improve educational attainment for a disadvantaged student population."[279] Moreover, universal preschool provides noticeable economic benefits to both the educated child and all state residents in the form of future economic earnings.[280]

However, across the United States, state financed preschool enrollment varies extensively.[281] Several states offer state funded preschool to a majority of children aged four years old who live in their state.[282] For example, Wisconsin, Vermont, Washington D.C., Oklahoma, and Florida all provide preschool services to 70% or more of their population of four-year-old children.[283] Additionally, Iowa, Texas, Georgia, West Virginia, and New York offer preschool services to approximately half or more of the four-year-old children living in their respective states.[284] Conversely, eleven states—including North Dakota—provide less than 10% of their population of four-year-old children with state funded preschool services.[285]

Specifically, during the 2018-2019 school year, "North Dakota preschool [only] enrolled 1,062 children . . . an increase of 97 4-year-olds from the prior year."[286] Moreover, North Dakota's "funding totaled $564,009, up $13,172 (2%), adjusted for inflation, since [the] last year [and] State spending per child equaled $531 in 2018-2019, down $40 from 2017-2018, adjusted for inflation."[287] The State of North Dakota, through increased funding, is in a position to provide universal access to preschool to all three and four year old North Dakota children.[288] By providing universal preschool to all North Dakota children, the State of North Dakota will: aid every North Dakota child's development, adequately identify children who may have an

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[278] *Id.*

[279] *Id.*

[280] Timothy J. Bartik, *The Economic Development Benefits of Universal Preschool Education Compared to Traditional Economic Development Programs*, W.E. UPJOHN INST. FOR EMP. RSCH. (2006), https://research.upjohn.org/cgi/viewcontent.cgi?article=1044&context=reports ("High quality preschool has been shown by rigorous research studies to significantly raise the earnings of participants. From this research, we know enough to say that high-quality preschool has economic development benefits that are large relative to its costs.").

[281] Allison H. Friedman-Krauss et al., *supra* note 275, at 14.

[282] *Id.*

[283] *Id.*

[284] *Id.*

[285] *Id.* (explaining that these eleven states were "Rhode Island, North Dakota, Alaska, Washington, Missouri, Nevada, Delaware, Mississippi, Arizona, Hawaii, and Montana").

[286] *Id.* at 139.

[287] *Id.* (the study concluded that "North Dakota met 2 of 10 quality standards benchmarks" that they used in their study).

[288] *Id.* at 6 ("Unless states greatly accelerate their efforts, it will be centuries before the United States reaches levels of preschool attendance now common in other high income nations.").

undiagnosed IDD or developmental delay, and promote the collective economic well-being of the next generation of North Dakota citizens.

b. Developmental Disability Services for Children Aged Three to Six

North Dakota should create new eligibility criteria for children with an IDD aged three to six years old so they may obtain access to Developmental Disability Services, namely HCBS. As outlined in Alvarez & Marsal's Study, North Dakota should revise its definition of "developmental disabilities" to instead "requir[e] significant functional limitations in two of the following three areas of adaptive functioning: conceptual, social, and practical."[289] This revision would expand access to the ID/DD Waiver to children with an IDD aged three to six years old by applying adaptive functioning versus the current format, which applies deficiencies in "major life activities."[290] The main obstacle in applying "major life activities" factors such as "Self-direction," "Capacity for independent living," and "Economic sufficiency," to children aged three to six years is that it imposes adult-based criteria upon children. Additionally, these adult-based criteria are ill suited to assist North Dakota providers in determining whether a child has an IDD or IDD condition. Therefore, it is prudent to evaluate children aged three to six years for adaptive functioning instead of "major life activity" like multiple North Dakota peer states already do.

Moreover, the author recommends North Dakota apply the findings and conclusions of Alvarez & Marsal's Study by permitting children aged three to six years to be served under a comprehensive IDD and ASD Waiver.[291] Moreover, the author recommends adding the Medically Fragile Waiver under this comprehensive waiver. Such a waiver would benefit all children aged three to six years who have an IDD, including ASD, or who are medically fragile. Thereafter, as stated in Alvarez & Marsal's Study, after a "transition point" and LOC reassessment, children aged six years and above "with intellectual disabilities, developmental disabilities, autism, and those that are medically fragile" should be served under a "Cross Disability Individual and Family Support Waiver."[292] Permitting children aged three to six years with an IDD—including those children who are medically fragile—

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[289] Alvarez & Marsal, *supra* note 36, at 26; *but cf.* N.D. CENT. CODE § 25-01.2-01(3) (requiring a "developmental disability" cause "substantial functional limitations in three or more of the following areas of major life activity: (1) Self-care; (2) Receptive and expressive language; (3) Learning; (4) Mobility; (5) Self-direction; (6) Capacity for independent living; and (7) Economic sufficiency").

[290] Alvarez & Marsal, *supra* note 36, at 26.

[291] *Id.* at 32-33.

[292] *Id.* at 33.

to obtain HCBS services will ensure these children reach their full potential. Additionally, creating a category that includes children aged three to six years will effectively bridge the gap between early intervention and kindergarten time periods and promote greater identification of children with an IDD, or an IDD condition, so they do not fall through the cracks or experience a gap in child development-based services.

2. *Removing Waitlists from North Dakota Home and Community-Based Services Waivers*

Finally, the State of North Dakota should remove all waitlists for child based HCBS Waivers, including the Autism Spectrum Disorder and Medically Fragile Waivers. Alvarez & Marsal's Study demonstrated how North Dakota's HCBS Waivers have different eligibility requirements and funding support, which creates "disparate access to services."[293] Currently, if children with an IDD meet the eligibility requirements for either the Autism Spectrum Disorder or the Medically Fragile Waivers, they are included in a queue on the waiver's respective waitlist.[294] However, while these children wait for their number to arrive in the waitlist queue, they do not receive necessary developmental services. The result is that children who need, and meet eligibility criteria for, these developmental services are effectively denied them until a new spot opens on the waitlist. This is harmful to both the individual child and society. Therefore, prudence requires intervention by the State of North Dakota to remove these waitlist barriers.

VI. CONCLUSION

Parents of children with an IDD are the primary advocates for their children. However, parents do not have the power or resources that federal, state, or local governments have to effectively advocate for children with an IDD. Luckily, both federal and North Dakota laws offer guarantees to parents of children with an IDD that their children will not be left behind solely because they have an IDD. Nevertheless, the State of North Dakota can promote both compassion and economic sustainability by expanding access to special education and developmental disability services to children with an IDD.

Specifically, North Dakota should offer expansive special education access and create new developmental disability eligibility criteria for children aged three to six years through greater use of the "Non-Categorical Delay" criteria and by creating a comprehensive IDD and ASD Waiver. Additionally, North Dakota can promote compassion and justice by removing

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[293] *Id.* at 16.

[294] *Id.* at 40.

artificial waitlist barriers for children with an IDD—including autism spectrum disorder—or for children who are medically fragile. Much like how children with an IDD must borrow their parents voice, in turn, parents of children with an IDD must borrow the voice of their governmental officials. By enacting these changes to expand children’s access to intellectual and developmental disability services, North Dakota will communicate to all parents, including those who have children with an IDD, that it will be the voice for children who are unable to speak for themselves.