Myth-Busting: Supporting Young Children With Intellectual and Developmental Disabilities Who Have Experienced Maltreatment

Mia Chudzik, MEd; Catherine Corr, PhD; Michaelene M. Ostrosky, PhD

Abstract

Estimates of the prevalence of children with disabilities in the child welfare system vary, as only a handful of researchers have investigated this topic. Yet, research has shown that children with disabilities are more likely to experience maltreatment compared to children without disabilities. While *all* children with disabilities are at greater risk of experiencing maltreatment, those with intellectual and developmental disabilities (IDD) may be at a higher risk. In this article, we summarize the data on maltreatment and its intersection with data on children with disabilities. We then discuss six common myths around children with IDD and offer alternative ideas and viewpoints. Addressing these misconceptions will help child welfare professionals better understand and support children with IDD.

Keywords: maltreatment, disabilities, children, intellectual disability

What Is a Disability?

Over three million children ages birth to 18 in the United States have a disability (Young & Crankshaw, 2021). While there are multiple ways to define disability, the Individuals with Disabilities Education Act (2004) defines a disabled individual as one who:

> *"(1) has an intellectual disability, hearing impairment (including deafness), speech or language impairment, visual impairment (including blindness), serious emotional disturbance, orthopedic impairment, autism, traumatic brain injury, other health impairments, or specific learning disabilities and (2) who, by reason thereof, needs special education and related services."*

A disability can impact a variety of developmental domains including communication, motor, cognition, and social-emotional skills (Young & Crankshaw, 2021). However, children with disabilities have many strengths as well as areas in which they need specialized support.

Some children are born with an identifiable disability, such as Down syndrome, whereas others may be diagnosed with a disability later in life such as attention deficit hyperactivity disorder (ADHD), a learning disability, or autism. Other children may develop a disability because of an illness, injury, or as a result of maltreatment such as a traumatic brain injury. Some children have a disability that impacts specific developmental domains such as physical development or cognitive development, while others may have more global delays. Some children may be diagnosed with a developmental delay, which refers to a significant variation in developmental milestones for one's age, such as walking, talking, and eating. While a developmental delay may not be permanent, as in the case of a child who may not be walking at 16 months

of age and starts to walk at 22 months, this diagnosis is commonly used for young children so they may access and receive supports such as speech-language therapy, physical therapy, occupational therapy, or developmental therapy (Batshaw et al., 2019).

One type of disability is an intellectual and developmental disability (IDD). This term is often used to describe a disability that is usually present at birth and affects an individual's physical, intellectual, and/or emotional development (Batshaw et al., 2019). An IDD can impact a child's ability to learn, reason, and problem solve. It also can impact adaptive behavior, which includes everyday social and life skills such as interacting with peers, dressing, toileting, and eating. While all children with disabilities are at a greater risk of experiencing maltreatment compared to children without disabilities (Jones et al., 2012; Sullivan & Knutson, 2000; Zetlin, 2006), those with significant support needs, such as children with IDD, may be at a higher risk (Child Welfare Information Gateway, 2018; Jones et al., 2012; Lightfoot, 2014).

Prevalence of Maltreatment Among Young Children With Disabilities

Estimates of the prevalence of young children with disabilities in the child welfare system vary for a few reasons. First, child welfare systems were not required to report information about a child's disability status until the 2010 reauthorization of the Child Abuse Prevention and Treatment Act (CAPTA) (Lightfoot, 2014). This reauthorization required that state child welfare agencies report the number of children under age three involved in a substantiated case who are eligible for early intervention services (i.e., special education) and the number of children under three who were referred for services. However, the child welfare system does not require the documentation of information regarding types of disabilities or the number of children with disabilities who are older than age three when they enter the child welfare system (Child Welfare Information Gateway, 2018). Moreover, while it is the responsibility of professionals in the child welfare

system to report data on disability, they often lack training focused on disability and special education services (Lightfoot & LaLiberte, 2006; Orelove et al., 2000). Specific challenges that these professionals may face include feeling unprepared to communicate with children with disabilities (Shannon & Tappan, 2011a) and being unable to identify a disability in children (Manders & Stoneman, 2009). Therefore, current estimates are likely conservative in terms of the number of children with disabilities within the child welfare system. This is problematic because when children with disabilities are not accurately identified and served within the child welfare system, they and their families are negatively impacted.

Child welfare professionals may be underprepared to support young children with IDD for a few reasons. First, despite understanding the importance of collaboration between child welfare and disability systems, there are often systemic barriers that make this collaboration difficult (Allen et al., 2012; Corr & Santos, 2017a, 2017b). The siloed nature of these systems can make it difficult to fully understand what each system does and how they could collaborate (Corr & Santos, 2017a, 2017b; LaLiberte & Lightfoot, 2013). Additionally, child welfare professionals have reported that they do not receive adequate training about disability and special education services (LaLiberte, 2013; Miller, 2018).

Despite these difficulties, some researchers have examined the prevalence of children with disabilities in the child welfare system. For instance, Sullivan and Knutson (2000) found that children with disabilities were 3.4 times more likely to experience maltreatment than children without disabilities. Similarly, Jones and colleagues (2012) reported that children with disabilities were 3.68 times as likely to experience maltreatment. Additionally, according to the U.S, Department of Health and Human Services (HHS), 14.1% of children who experienced maltreatment in 2015 had a disability (U.S. HHS, 2015). These findings, though limited in number, and somewhat variable, are startling and are a cause for concern and focused attention.

Why Children With Disabilities Are More Likely to Experience Maltreatment

Many factors may contribute to the higher prevalence of children with disabilities experiencing maltreatment. Children who rely on caregivers to have their daily needs met (i.e., feeding, dressing, bathing) may experience a lack of independence and privacy (Hibbard et al., 2007; Zablotsky et al., 2019). Compounding this, some of these children may have a limited ability to protect themselves, to communicate, or to understand what maltreatment is or whether they are experiencing it (Lightfoot, 2014). Additionally, added stress in caregivers' lives due to social isolation, children's intensive needs, and children's challenging behaviors may contribute to high rates of maltreatment (Shannon & Tappan, 2011b; Sobsey, 1994). Finally, it may be hard for caregivers to determine whether a behavior such as hitting, crying, or social withdrawal are due to a child's developmental age, disability, or maltreatment, causing them to overlook possible signs of distress (Lightfoot, 2014).

In addition to children with disabilities being more likely to experience maltreatment compared to children without disabilities, the risk and prevalence of maltreatment varies based on the type of disability. Consider, for example, a child with an IDD who has a communication delay or communicates in an alternative way, such as by using an augmentative or alternative communication system. If this child experiences abuse or neglect, they may not be able to alert a trusted adult to this, and adults who support this child may feel unprepared to determine how to best support them. Additionally, children born with congenital disorders that may lead to medical complications such as Down syndrome or spina bifida are at an increased risk of experiencing maltreatment in the first month of life (Van Horne et al., 2015). This type of maltreatment may occur when medical care is withheld by a caregiver, such as when a child born with a heart defect is denied surgery.

Due to the increased risk of children with disabilities experiencing maltreatment, it is important that child welfare professionals are cognizant of the relationship between disability and maltreatment. Professionals also need to have the knowledge, skills, and confidence to support young children with IDD in the child welfare system.

Myth Busting

Previous research has highlighted the need to better support children with disabilities who have experienced maltreatment. Despite this perceived importance, child welfare professionals report feeling unprepared to do so (Corr & Santos, 2017a; Orelove et al., 2000; Shannon & Tappan, 2011a, 2011b). Below, we discuss six common myths about children with IDD and offer alternative ideas and ways of thinking.

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Myth: Children with disabilities are best understood through the medical model.

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Reality: Using the social model can help promote better understanding of children with disabilities.

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The medical model focuses on disability as an impairment that is impacting the individual (Ladau, 2021). This model can be problematic when working with children with disabilities, as it puts the onus on the individual. A different way to view disability is through the social model. According to this model, individuals are not disabled by their impairments or medical conditions, but by systems, attitudes, and environments that create barriers to access and participation (Cole, 2007; Ladau, 2021). This is generally in opposition to the medical model of disability, which places the blame for a child's inability to "do something" on the individual and their disability (Ladau, 2021). Viewing disability through the social model may help child welfare

professionals better understand how to best support children with IDD, as it encourages looking at physical and social environments and assessing how they can be changed to support the child as opposed to focusing on fixing the child. For example, if a child in a wheelchair attempted to enter a building that only had stairs, the medical model would focus on the child's disability (i.e., the child cannot walk up the stairs). The social model would recognize that the problem stems from the fact that the building is not accessible.

It is also important to note that while children with disabilities are at an increased risk of experiencing maltreatment, it is not the disability itself that causes this increased risk, but instead society's response, or lack of response, to disability through discrimination, a lack of support, and barriers to accessing services (Lightfoot, 2014; Shannon & Tappan, 2011a).

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Myth: Child welfare professionals need to work on their own to support a child with IDD.

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Reality: There are other professionals who can support child welfare professionals in their work with children with IDD.

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The importance of collaboration between the child welfare system and disability-related systems, such as early intervention (Corr & Santos, 2017a, 2017b; Dicker & Gordon, 2006; Shannon, 2021) and the special education school system (Zetlin, 2006), has been established. Cross-system collaboration is needed because no one system can meet the complex needs of families and young children with disabilities who have experienced maltreatment (Corr & Santos, 2017a). For very young children ages birth to three served in the early intervention system, reading their Individualized Family Service Plan (IFSP) and talking with the early intervention team can be helpful. A child's IFSP will contain information about

goals for the family and child that can be worked on in the child's natural environment, such as at home or at the park. The child's service coordinator should be able to share information and help professionals within the child welfare system learn more about an individual child's strengths and needs. Children over the age of three typically are served through the special education system in their local public schools. A child's special education teacher can provide valuable insights into the child's strengths and strategies that are used to support the child, as well as answer questions. Additionally, looking at the child's Individualized Education Program (IEP) can provide further insight into supports the child receives at school. Strong collaborative relationships can improve access to and the quality of services that children with disabilities who have experienced maltreatment receive (Corr & Santos, 2017a; Dicker & Gordon, 2006). See Table 1 for additional information about IFSPs and IEPs.

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Myth: The only way children can communicate is verbally.

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Reality: Children with IDD communicate in a variety of ways.

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Children communicate in many ways in addition to talking. For instance, eye gaze, vocalizations, picture systems, and sign language are common and effective ways to communicate. Children with IDD may communicate in other ways as well. Some children may use an Augmentative and Alternative Communication (AAC) device, such as a picture system or a computer to communicate. While child welfare professionals do not need to be experts in all forms of communication, it is important to know what a child's primary form of communication is and to recognize and respect that it is a valid form of communication. If interested, child welfare professionals can enlist the help of someone who is able to communicate with the child using that

communication system or someone who has more knowledge of the communication system, such as the child's caregiver, special education teacher, or speech language pathologist. The child's IFSP or IEP should include additional information about their communication style.

Myth: It is impossible to take a strengths-based approach with children with IDD.

Reality: Using a strengths-based approach is the best way to support children with IDD.

When taking a strengths-based approach, professionals focus on identifying the developmental competencies of the child, rather than simply noting what the child cannot do (Brunzell et al., 2016; Burdick & Corr, 2021). For example, rather than seeing a child as "nonverbal," it is important to focus on how and when the child makes their needs and wants known through eye gaze, vocalizations, shaking their head, or other forms of communication. Identifying a child as nonverbal is not helpful because it only focuses on what the child cannot do—not the ways in which they can and do communicate. By using a strengths-based approach, professionals can better understand and support children with IDD. Using a strengths-based approach as a child welfare professional can be beneficial because it helps provide a better understanding of the child and can set the stage for fostering strong relationships with them.

Myth: Child welfare professionals have to learn to support the child they are working with on their own.

Reality: Using a family-centered approach can help child welfare professionals learn from those who know the child best.

As a child welfare professional, it may feel as if you are on your own when trying to support a child with IDD. However, taking a family-centered approach may be helpful. A family-centered approach focuses on supporting the family as a whole, honoring their strengths, and promoting their active engagement (Child Welfare Information Gateway, 2018; Dunst & Espe-Sherwindt, 2016). In this capacity, "family" can mean more than just biological parents. It also can include childcare providers, relatives, foster parents, or anyone else who provides care for the child. Taking a family-centered approach when working with children with IDD is important, as these caregivers are the most knowledgeable about the child, their strengths, and their needs (Dunst & Espe-Sherwindt, 2016). One key component of family-centered practices includes building relationships with everyone who provides care for a child, including foster parents or childcare providers. This can be done by finding out who the child is close with, contacting them, and asking questions to learn more about the child and how to best support them. These individuals typically have valuable insights about the child and can help child welfare professionals gain a better understanding of the child's strengths and needs.

Myth: The preferences and priorities of children with IDD do not matter.

Reality: Children with IDD have their own thoughts, experiences, and preferences.

Children with IDD have their own individual thoughts, experiences, and preferences. One way to think about this idea is by understanding the concept of self-determination, which refers to a child's ability to act as the primary causal agent in their life (Wehmeyer, 1996). Supporting children's self-determination requires professionals to recognize them as full people and honor their voices, choices, and preferences. For children with IDD, this might take the form of recognizing and supporting their use of assistive technology or allowing them to

share their opinions and thoughts on a topic. A child's IFSP or IEP can help with this, as these support plans include information about a child's present levels of development, their strengths, and modifications that will help them succeed. Reading this document can provide insights into the child's preferences and priorities. Additionally, a child's special education teacher or early intervention provider can provide more information on this, based on their interactions and work with the child and their family.

Conclusion

Research has shown that children with disabilities are at an increased risk of experiencing maltreatment. Because of this, it is important that child welfare professionals consider how to best support these children. Table 2 includes information on some professional organizations and resources focused on disability and special education; child welfare professionals can peruse these to learn more about supporting young children with IDD. Additionally, while child welfare professionals may not have received training related to disability, there are other professionals they can collaborate with to gain more information and support. Special education professionals, such as early intervention providers or classroom teachers, can provide useful insights into children's' strengths and strategies for supporting them. Childcare providers or other caregivers also can provide support and serve as important resources. Finally, it is important to view children with IDD through a strengths-based lens and assume competence. This can be done by viewing disability through the social model and focusing on what children can do. By using these strategies, child welfare professionals can better support children with IDD who have experienced maltreatment.

Table 1

Information about IEPs and IFSPs

Adapted from the Pacer Center

Individualized Family Service Plan (IFSP)	Individualized Education Program (IEP)
Used in early intervention for children ages birth to three and their families	Used in special education for children ages three to 21
Services are provided in the natural environment (home, childcare)	Services are provided in school
Goals focus on child and family needs	Goals focus on educational needs of the child
Includes information on the child's present level of development, goals for the child and family, and services the child and family will receive to help them achieve the goals	Includes the special education services (speech therapy, physical therapy, occupational therapy), related services, and modifications the child will receive in school
Team members include caregivers, service coordinator, and other professionals that are providing services (speech-language pathologist, physical therapist, occupational therapist)	Team members include caregivers, general education teachers, special education teachers, and other professionals who are providing services (social work, speech-language pathologist)

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Table 2

Disability Organizations and Resources

Resource	Website	Description
Division for Early Childhood (DEC)	https://www.dec-sped.org/	The Division for Early Childhood (DEC) is an organization for those that work with or on behalf of young children with disabilities.
Division on Autism and Developmental Disabilities (DADD)	http://www.daddcec.com/	The Division on Autism and Developmental Disabilities (DADD) is an organization of individuals committed to enhancing the quality of life of individuals with IDD.
Center for Parent Information and Resources	https://www.parentcenterhub.org	This website provides additional information about IEPs and IFSPs in a jargon-free manner.

About the Authors

Mia Chudzik, MEd, is a doctoral student in the Department of Special Education at the University of Illinois at Urbana-Champaign. Her research interests include trauma-informed care in early childhood special education.

Catherine Corr, PhD, is Associate Professor in the Department of Special Education at the University of Illinois at Urbana-Champaign. Her primary research interests include early childhood special education, trauma, and the use of mixed methods research designs in special education research.

Michaelene Ostrosky, PhD, is Professor in the Department of Special Education at the University of Illinois at Urbana-Champaign. Her research focuses on early childhood special education with a particular interest in inclusion, social emotional competence, peer relationships, and challenging behavior.

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