Depression in Parents of Children With Developmental Disabilities: What Do We Know and What Can We Do?

Family & Community Health

Date Posted:

Nov 15, 2018



Parental depression is a common condition, and for parents of children with developmental disabilities—both moms and dads—it is even more likely that they will report symptoms of depression than parents of children without disabilities. As providers who care for youth with disabilities, we know how important it is to address parental symptoms of depression in order to support healthy growth and development for children. If unrecognized and/or untreated, parental depression can have a huge impact on how the family functions, and on how a parent and child are able to bond.

Why are rates of depressive symptoms higher among parents of children with special needs?

Although we know that there is an association between depressive symptoms and having a child with a developmental disability, we still have much to learn in order to provide effective and responsive supports to families.

Having a child with a developmental disability can be stressful, even while parents describe it as being rewarding. Some developmental diagnoses are considered life-long chronic conditions that may require ongoing parental support beyond the age that other children reach independence. Children with developmental disabilities may also have one or more significant medical problems that require intensive and ongoing care. Furthermore, many of the therapies recommended for young children depend on parents to implement strategies at home throughout the day, presenting additional demands for parents. Parental depression can

interfere with the correct implementation of these interventions, and can even counteract the effects of home-based interventions.

Other factors are at work as well. Financial stressors tend to be higher among parents of children with developmental disabilities, which may negatively impact parents' mood and well-being. Characteristics of the child, including behavioral difficulties such as aggression, can contribute to the risk of parental depression. And many developmental conditions can affect a child's ability to sleep independently throughout the night, contributing to parents' sleep deprivation and exacerbating depressive symptoms.

While many parents of children with a disability experience stigma and frustration with services, the nuances of the parent's experience can vary greatly across diagnoses. For example, many families of children with autism spectrum disorder (ASD) report feeling isolated, and describe their reaction to a new diagnosis of ASD as a grieving process similar to having lost a child, which can increase depressive symptoms. Conversely, having positive parent-child relationships can protect against depression.

Symptoms of parental depression and a child's developmental and behavioral problems are likely closely intertwined. Having severe depressive symptoms can affect a parent's ability to respond to a young child's needs, putting them at risk for physical and emotional health issues and poor social skills later in life. This highlights the need for providers of children with developmental and behavioral disabilities to assess and support parents' mental health needs as well.

Recent research results

A recent study at Children's Hospital of Philadelphia (CHOP)/Penn Nursing surveyed 245 mothers about their depressive symptoms, family functioning (the ability of a family to meet the needs of all family members), self-efficacy (a parent's feeling of confidence in caring for their child) and child's behavior. More mothers of children with ASD screened positive for depression compared to moms of children with Down syndrome (Trisomy 21) and children with typical development (24 percent vs. 12 percent vs. 0 percent). Furthermore, 37 percent of moms of children with ASD and 20 percent of moms of children with Down syndrome reported a history of a mental health diagnosis (e.g. depression, anxiety, bipolar) before giving birth to their child. Moms of children with ASD were more likely to report a personal and family history of depression than the other groups.

This research is ongoing, but parenting self-efficacy and family functioning appear to be related to a child's diagnosis, as well as to symptoms of maternal depression. This suggests that in order to improve parental depression, we need to support parents' self-efficacy and the family dynamics as a whole.

How can we support families of children with disabilities?

At PolicyLab, we're looking closely at ways to identify and address parents' physical, social and mental health needs in order to improve children's health and well-being. Parental depression goes largely unidentified and untreated, and supports for parents of children with special needs remain limited. Clinicians and pediatric health systems should implement parental depression screening programs in clinical settings that treat children with disabilities and provide resources when symptoms of depression are identified.

Finally, helping parents feel more capable and effective in caring for their child with special needs may reduce the risk of depression. A simple word of acknowledgement and encouragement can make a huge difference for a struggling parent. Enhancing access to increased social supports, through respite services or support groups, may help parents manage their own stress and feelings of isolation. One mom of a child with Down syndrome and ASD described her social network to us as being "worth its weight in gold." Every family caring for a child with a disability should experience that same sense of support.

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Nursing. She is currently working on her doctoral dissertation, which is a mixed-methods study focused on identifying depression symptoms in mothers of children with autism spectrum disorder, trisomy 21 and typical development, and on characterizing modifiable risk factors for maternal depression in these populations.

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