Supporting Fathers of Children With Special Needs

Approximately 20 percent of U.S. children under the age of 18 require special accommodations or services due to a chronic physical, developmental, behavioral, or emotional condition, and 65 percent of these children need comprehensive services in addition to prescription medications. This poses significant challenges, worries, and concerns for their parents, and fathers in particular may feel overwhelmed as they struggle to find solutions. Informed fatherhood practitioners can provide support for fathers and help them understand the needs of their children.

The National Responsible Fatherhood Clearinghouse (NRFC) has developed this research brief to help fatherhood practitioners increase their awareness and understanding of the experiences of fathers of children with special needs. The brief explains several of the more common special needs, describes challenges that fathers of children with special needs may face, and provides tips to help fatherhood programs better support these fathers. Because most research on the experience of parents of children with special needs has focused on mothers, we draw from both published research and interviews with program staff who have experience in serving fathers with children with special needs.

Overview of Common Special Needs

Attention deficit hyperactivity disorder (ADHD), which affects many more boys than girls, is a brain disorder marked by an ongoing pattern of inattention and/or hyperactivity that interferes with functioning or development. Characteristics may include:
- Struggling to follow through on instructions.
- Being easily distracted or forgetful (e.g., losing materials that are necessary for tasks or activities).
- Talking excessively or blurtling out answers before questions have been completed.

Autism spectrum disorder can cause significant social, communication, and behavioral challenges. It may affect individuals’ learning, thinking, and problem-solving abilities. Affected children:
- Typically have a difficult time developing communication and social skills.
- May display repetitive behaviors and be sensitive to stimuli such as sound, light, smell, or touch.
- Often do best when they have a consistent routine for their daily activities.
- May show single-minded interest in a topic or, in rare cases, display unique and specific knowledge of a topic that is more focused than the knowledge other children have.

Cerebral palsy is caused by abnormal development of, or injury to, the part of the brain involved in movement while the brain is still developing. Motor impairment is the primary symptom. Children with cerebral palsy:
- Have difficulty with movement or muscle coordination.
- Often have seizures; an intellectual disability; and/or speech, vision, and hearing difficulties.

Developmental delays occur when children do not meet expected milestones in their physical, social, emotional, intellectual, speech, or language development. These delays:
- Are typically diagnosed when a child is performing 25 to 30 percent below the norm for their age.
- Can be long term, but are often temporary or can be diminished if appropriate interventions are provided (the earlier an intervention is provided, the greater the likelihood of a successful impact).

Down syndrome is a genetic condition with physical development delays and intellectual disabilities that may include:
- Mild to moderate cognitive delays (although there is a lot of variability in degree of impairment).
- Distinctive facial features, a small stature, and low muscle tone.
- Heart defects and higher risk for respiratory infections at birth; seizures; and hearing, sight, and dental problems.
**Intellectual disabilities** are broadly characterized by:

- Significant limitations in intelligence or mental capacity.
- Significant limitations in levels of conceptual skills, practical skills, and social skills.\(^7\)

**Challenges Faced by Fathers of Children with Special Needs**

Parents of children with special needs are faced with unexpected challenges that can be overwhelming, and they often experience feelings of grief as they struggle to adapt to their situation. In addition to the typical stressors associated with parenting, they face unique stressors related to their child’s special needs. However, with support, parents can navigate their situation and, ultimately, enjoy a rewarding journey of resilience.\(^8\)

Although fathers and mothers typically have many of the same needs and concerns, there are often significant differences in how they respond to their child’s condition, what they do to cope, and what they find helpful.\(^9\) For example:

- Caring for children with special needs may require a very specific structure and routine, and parents may find it difficult to balance home life with employment and other demands. A common experience among fathers of children with special needs, which has been referred to as “hunter-provider anxiety,”\(^10\) is a fear of failing to find or keep steady employment; balance their roles as fathers, husbands, and providers; and provide other necessary support for their child. Although this can be a concern for all fathers, the high cost of medical or therapeutic care and other services brings additional worries for fathers of children with special needs.

- While mothers often have friends they can talk with about their struggles, fathers are less likely to either have close social networks or feel comfortable talking about their concerns, which can lead to feelings of isolation and social withdrawal.\(^11\) Also, because fathers often want to take immediate action and “fix” things, they may feel inadequate if they don’t know how to support their child’s needs or find solutions to the issues.\(^12\)

- Although divorce rates of parents of children with special needs are nearly identical to divorce rates of other families, practitioners note that parents of children with special needs often report low rates of marriage satisfaction and increased difficulties with their partner.\(^13\) In addition to high levels of marital stress, fathers of children with special needs commonly experience greater levels of parenting and child-related stress compared to fathers whose children do not have special needs. The increased stress level is often caused by concerns about their child’s behavior, social acceptance of the child, and what their child will be able to accomplish. It is important to note, however, that the types of stressors vary by a child’s diagnosis. For example, a child with cerebral palsy may require special equipment at home and/or school to navigate physical barriers, like stairs. This requires an investment of parents’ knowledge, monetary resources, and time to find solutions, but it may not cause chronic psychological stress, especially if parents are able to overcome those challenges. Parents of a child with an intellectual disability, on the other hand, may worry that their child will be a victim of abuse because these children are at a greater risk for abuse than children without special needs.\(^14\) This risk may increase psychological stress, as it is always in the back of parents’ minds.

- While perceived inadequacies in meeting the needs of their child or spouse accounts for some of this stress, fathers can also be affected by concerns that they are not playing a primary role in their child’s care and development. They may feel that the mother is in control of their child’s care and is more knowledgeable about the child’s needs.\(^15\)

**Addressing the Parenting Needs of Fathers of Children with Special Needs**

To help fathers of children with special needs address the challenges they face, fatherhood practitioners should be aware of the range of common needs and diagnoses; know how to provide relevant information, support, and guidance on an individual level; and be able to direct fathers to helpful resources or specialized services. For example, fathers may not understand the difficulties of connecting and bonding with some children whose symptoms include social impairment. It is important for fatherhood practitioners to emphasize that child developmental processes vary considerably and there is no one-size-fits-all approach.

Fathers will often need practical support to identify and attain services for their children. This can include documentation of special needs to qualify the child for an individualized education program, completion of forms to obtain disability living allowance, or referrals to qualified caregivers.\(^16\) Knowledgeable staff can:

- Provide information about specific developmental needs and how fathers can respond appropriately.
• Help fathers understand the options for any indicated accommodations and treatment.
• Explain what financial resources and assistance might be available.
• Make referrals to relevant local or online services.

Fathers of children with special needs also need emotional support. Program staff have reported that fathers not only want specialized and personalized information about their children, but they also benefit from social support and connection with other fathers. The most beneficial form of support can often be helping fathers feel that they are “not in this alone.” They can get this support from participation in general fatherhood groups, particularly when the groups are offered on a flexible evening or weekend basis, but they will find the most connection in groups with fathers who are in similar situations.

Program staff have also reported that, compared to fathers in general, fathers of children with special needs tend to be more interested in programming that includes the child and other family members rather than programming for fathers only. Programs that cater to all family members, to fathers and mothers, or to fathers and children together are often more appealing for these fathers. Given the high levels of marital stress, parents can also benefit from couples workshops or counseling to help them strengthen their bond and work together to care for their child.

Tips for Staff Working With Fathers of Children with Special Needs

• Provide information on specific conditions, but emphasize that every child is unique and his or her needs can vary greatly in terms of developmental impairment and severity of impairment.
  o For fathers with young children, emphasize the importance of early screening for developmental delays or learning disabilities. Early detection and intervention can significantly improve a child’s long-term outcomes.
  o For relevant information, see The Arc, Family Voices, and other resources listed at the end of this brief.
• Prompt fathers to think about their child’s unique strengths and positive qualities.
• Help fathers accept and understand their child’s diagnosis and their own resulting emotions. Use positive and strength-based language to guide acceptance of their child as he or she is, and recognition of the child’s unique strengths.
  o Emphasize that fathers cannot “fix” health problems or disabilities, but they can take action to improve outcomes for their children. For instance, fathers can learn how to navigate the Medicaid and health care systems and take advantage of various tax breaks.
• Meet fathers “where they are” in terms of knowledge.
  o Don’t assume that the father is knowledgeable about the child’s special needs. Often, fathers are unable to attend doctor appointments, doctors talk more to mothers than to fathers, and doctors don’t have enough time to give thorough explanations.
  o If fathers feel overlooked at their children’s medical appointments, help them feel empowered to engage with doctors and advocate for themselves as a caregiver.
• Help fathers stay organized. Provide ideas to help them maintain contact information for doctors, schools, and other providers and track medical information such as records, appointments, and medications.
• Be aware of fathers’ stress levels and encourage self-care. Suggest ways they can take care of themselves. For example:
  o Spending alone time or adult time with their partner and/or friends.
  o Exercising, eating well, and getting enough sleep.
  o Seeking help and support from loved ones or professionals when in need.
  o Carving out time to do things they enjoy.
• Connect fathers with other fathers who have experienced or are facing similar situations. Depending on the number of fathers facing similar situations, opportunities for connection could involve mentoring, one-to-one sharing, peer support forums, or online matching with fathers experiencing similar challenges. This can be invaluable in countering the isolation that often accompanies fathering a child with special needs.
  o Rather than calling the forum a “support group,” which can have a negative connotation for some men, consider alternate names such as “men’s group,” “fathers’ network,” “mentoring group,” or “coaching circle.”
  o Depending on the number of fathers, consider holding groups for specific subpopulations, such as fathers of children with Down syndrome or fathers of children on the autism spectrum.
Set up social occasions for fathers to meet and exchange ideas.
Schedule father-and-child activities that enable fathers to spend time with, and learn from, other dads and their children.
Host informal meals or social events where men can develop contacts for ongoing support.

Teach skills to help fathers become their own advocates. One way to do this is to role-play interactions with a teacher, a school administrator, a doctor, and other professionals who fathers may be in contact with regarding their child’s needs.

Provide communication classes for couples.
Consider providing specialized co-parenting services for mothers and fathers who do not live together to help them work together to parent their child with special needs.

Collect information on local, state, and national resources that can be useful tools for fathers.
Develop partnerships with local individuals or organizations that support families of children with special needs or provide other helpful resources or services.

Make sure these individuals or organizations understand the services provided by your fatherhood program and the challenges experienced by fathers of children with special needs. This can help fathers feel more comfortable if they are referred for assistance.

Develop referral lists to help fathers identify or locate assistance that may be available in their community.

Helpful Resources

The Arc is a network of more than 600 state and local chapters that provide information, services, and supports for people with intellectual and developmental disabilities and their families.

Building Partnerships Between Parents and Practitioners, from the National Council for Curriculum and Assessment, provides information about building a partnership between parents and practitioners to support children and families.

The Cerebral Palsy Guide, a resource for parents of children with cerebral palsy, includes tips for making time for self-care and staying organized.

Dads Appreciating Down Syndrome provides support for fathers and families of individuals with Down syndrome. They have 57 U.S. chapters unified by the theme, “We came together for our kids. We stay together for each other.”

Family Voices is a national network focused on family-centered care for children and youth with special health care needs. The organization maintains a list of affiliated programs across the U.S.

Good Practice in Working With Parents of Disabled Children, a briefing paper from the U.K.’s National Academy for Parenting Practitioners, provides information about children with special needs.

A Guide for Working With Parents of Children With Special Educational Needs or Disabilities (SEND), from the U.K.’s National Charity All About Children and Families, provides information to help practitioners talk with parents about their child’s needs.

The Hanen Centre provides information and guidance for parents of children with autism on how to support their child’s communication development.

Strengths and Challenges Guide, from Autism Speaks, provides information on typical strengths and challenges among children diagnosed with autism spectrum disorder.

Washington State Fathers Network, a program of Kindering, provides support and resources for fathers of children with special needs. The Kindering website includes a page of resources for families and practitioners. The Special Needs Resources and Parent Involvement and Advocacy Resources may be particularly useful for fatherhood practitioners working with parents of children with special needs.

When Dads Engage Autistic Kids More, Everybody Wins is a report from PsyCen Central showing that fathers’ involvement with their children with autism has a positive effect on the child’s development and the mother’s mental health. This was found specifically for families in which both biological parents resided with the child.
Working With Dads of Children With Special Needs is a section in the NRFC’s Responsible Fatherhood Toolkit. The PowerPoint slides from a 2013 NRFC webinar (Working with Dads: Resources and Support for Fathers of Children with Special Needs) provide additional resources and information.

Working with Fathers of Children and Youth with Special Health Care Needs, a white paper by WC Hoecke, Family Connection of South Carolina, provides information for practitioners working with fathers of children with special needs.

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References