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Opportunities for Improving Programs and Services for Children with Disabilities

Although the general public in the United States assumes that children generally are healthy and thriving, a substantial and growing number of children have been diagnosed with at least one chronic health condition. Many of these persistent or long-lasting conditions are mild and do not significantly affect the child's ability to develop age-appropriate skills or complete the expected and preferred activities of daily life. However, many such conditions are associated with disabilities that interfere regularly with children's usual activities, such as play or leisure activities, attending school, family or community activities, and routine activities of daily living. And some conditions interfere with developmental processes and the attainment of functional skills such that the person's disability will be lifelong.

To help meet the highly diverse needs of children with disabilities, many programs and services to enhance health and functioning have been developed across a variety of domains, including health care, education, social needs care, and employment. Regular access to and use of quality, evidence-based programs and services positively impact health and functioning outcomes for children with disabilities.

With support from the Social Security Administration (SSA), a committee of the National Academies of Sciences, Engineering, and Medicine examined programs and services designed to enhance the health and functioning of school-aged children with disabilities. The resulting report, *Opportunities for Improving Programs and Services for Children with Disabilities*, describes the characteristics of effective programs and services; identifies their gaps and limitations; and aims to help inform opportunities for SSA and other federal, state, local, and private entities to

- improve the provision of services and supports to children with disabilities and their families,
- enhance the ability of programs and services to improve health and functioning outcomes for children with disabilities, and
- improve data collection and sharing, inspire a culture of innovation, and inform decisions about future research efforts.



ABOUT THE STUDY

Children with disabilities are highly diverse in terms of their health conditions, disability severity, social environments, and service and support needs. At the same time, children with disabilities share many of the same needs, so the committee used a non–disease-specific approach to disability in assessing programs and services designed to improve health and functioning outcomes of the broad population of children with disabilities.

Examples of large federal programs that provide supports to and aim to improve outcomes for children with disabilities include Supplemental Security Income (SSI), Medicaid, the Children’s Health Insurance Program (CHIP), special education and other school-based services guided by the Individuals with Disabilities Education Act (IDEA), and various other programs within or supported by U.S. Departments of Health and Human Services (HHS), Education (ED), Housing and Urban Development (HUD), and Labor (DOL), as well as SSA. The committee looked at programs through the lens of outcomes in health and in social and human capital development.

Three-quarters of the roughly 1.0 million school-aged children receiving SSI benefits live in households with income below 200 percent of the federal poverty level; approximately half are characterized as having mental disorders. The committee focused particularly on programs and services for children with severe mental, developmental, and speech and language disorders and the interactions between poverty and childhood disability.

THE COMMITTEE’S CONCLUSIONS

Based on its review of programs and services for improving health and functioning outcomes for children with disabilities, the committee carries out three primary tasks in its report: (1) describing the characteristics that contribute to the effectiveness of these programs and services; (2) identifying their gaps and limitations; and (3) providing findings and conclusions that can inform decisions about SSA involvement and future research efforts. Resulting from this work were 13 overarching conclusions.

Characteristics that contribute to effectiveness

The committee reached the following conclusion related to characteristics that contribute to the effectiveness of programs and services:

Conclusion 1: Children with disabilities need access to a wide range of quality programs and services that meet their individual needs and support smooth transitions to new and different programs and services across childhood and into adulthood. Eight specific

characteristics commonly contribute to the effectiveness of programs and services for children with disabilities and their families:

- Engaging children and families in the child’s care and building solid support networks for the child and her or his caregivers;
- Providing individualized services and supports based on an assessment of the child’s and family’s specific needs, strengths and weaknesses, and interests;
- Offering or connecting children and families to interventions that have strong evidence of efficacy or effectiveness, increase the likelihood of desired health and functioning outcomes, and are consistent with current professional knowledge;
- Having effective outreach strategies and helping connect families to needed supports;
- Helping children and families navigate the array of available programs and services and ensuring coordination of care within and across service sectors;
- Focusing on achieving specific near- and long-term goals that help children prepare for transitioning to adulthood;
- Increasing the child’s ability to negotiate new regulations, new expectations, new providers, new ambiguities, and greater responsibilities for accessing available programs and services as the child transitions to adult programs and services; and
- Engaging in rigorous quality control, including regular, systematic evaluation and continuous improvement activities.

Gaps and limitations

The committee reached two conclusions regarding gaps and limitations of programs and services:

Conclusion 2: Although a wide variety of services and programs exist to support the needs of children with disabilities and their families and encourage healthy growth and development, a variety of gaps and limitations create barriers to services and substantial variation in access to and quality of services. These include

- sociodemographic and socioeconomic disparities;
- geographic disparities;
- state variation in the implementation of federal programs;
- insufficient workforce capacity and development;
- fragmentation of services;
- limited, fragmented, and difficult to access information on programs and services;
- lack of preparedness for transitioning to adult services and programs; and
- gaps in continuity of care during transition to adult programs and services.

Conclusion 3: The evidence base for programs and services aimed at improving health and functioning outcomes for children with disabilities, although extensive in some respects (e.g., short-term impacts for selected interventions), is limited overall because of a number of factors, including

- wide variation in how disability and related outcomes are defined and measured;
- limited longitudinal data on health and functional outcomes;
- a lack of rigorous evaluation of programs and services, limited reporting of data, and variability and inconsistencies in the focus and level of detail of reported data;
- persistent challenges in information sharing across government agencies and a lack of integration across data systems; and
- inability to isolate effects of programs and services in an environment in which children may use different programs and services over time as their needs evolve.

Opportunities for improving the provision of services and supports

The committee formulated the following six conclusions regarding opportunities to help improve the provision of services and supports to children with disabilities and their families and to enhance the ability of programs and services to improve health and functioning outcomes for children with disabilities.

Conclusion 4: It is important that children, parents, health care providers, schools, and other support sectors encountered by children with disabilities work together in improving the health and functioning of children with disabilities. When all parties involved strive to create working alliances—where children believe that providers have their best interests at heart, value their contributions, and share in developing and helping them achieve their goals—the result is increased opportunities for ensuring children’s health and encouraging their positive growth and development.

Conclusion 5: Children with disabilities and their families need the information and tools necessary to understand treatment options, voice informed opinions and preferences regarding decisions about the child’s care, and engage in self-care.

Conclusion 6: Increased focus on issues related specifically to childhood disability during postsecondary and graduate education and in-service training programs across service sectors will facilitate greater understanding and more effective use of information

related to the children’s health and disability and lead to improved quality of services.

Conclusion 7: Children with disabilities and their families need better information about available programs and services for which they may be eligible.

Conclusion 8: Children with disabilities and their families will benefit from a more streamlined approach to accessing programs for which they may be eligible.

Conclusion 9: Identifying and remedying policies that produce age-based barriers to continuity of access or create disincentives for youth with disabilities to pursue long-term goals related to paid employment and economic self-sufficiency is important. Programs and services that encourage children with disabilities to pursue goals related to successfully transitioning to adulthood and long-term self-sufficiency, without fear of losing critical supports, can positively impact long-term outcomes.

Opportunities for improving data and research

Finally, the committee formulated the following 3 conclusions focused on opportunities for improving data collection and sharing, inspiring a culture of innovation, and informing decisions about future research efforts. It is in these areas that the committee identified the greatest potential opportunities for informing SSA involvement in efforts to improve the health and functioning outcomes of children with disabilities.

Conclusion 10: Improving programs and services for children with disabilities will require strategies to improve data and information on trajectories, outcomes, and interventions.

- Fully understanding chronic health conditions, their consequences, and their response to treatments requires data that follow the individual and the condition over time.
- Encouraging governmental (federal, state, and local) and nongovernmental programs to collect, synthesize, and publish data on their programs will support the dissemination of innovative programs for children with disabilities.
- Developing a more comprehensive reporting structure linking federal, state, and local administrative data systems could help foster a new understanding of the long-term outcomes of youth with disabilities into adulthood and help shape the next generation of programs and services for children with disabilities.

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Conclusion 11: Inspiring a culture of innovation is critical to improving health and functioning outcomes for children with disabilities. Achieving this will require

- rigorous evaluation of programs and services;
- testing, monitoring, and reporting health and functioning outcomes; and
- developing new and innovative approaches for supporting children with disabilities and their families.

Conclusion 12: SSA has an opportunity to improve the evidence base for programs and services for children with disabilities through an expansion of its demonstration projects beyond their previous and current focus on employment, independent living, and self-sufficiency and through partnerships with other federal agencies that serve children with disabilities.

IN CONCLUSION

To achieve optimal health and functioning outcomes, children with disabilities need access to a wide range of quality programs and services that meet their individualized and evolving needs, are coordinated within and across service sectors, and help them realize their full potential as they grow, develop, and transition into adulthood. Many national, state, and local programs—a number of which are highlighted in this report—offer a variety of services that enable eligible children and youth with disabilities and their families to function better and meet their support needs. There are ample opportunities to further develop, implement, evaluate, and improve programs and services and enhance their ability to optimize health and functioning outcomes for children with disabilities, enabling them to grow and thrive.

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To read the full report, please visit
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