

Viewing Services for Children and Youth With Special Health Care Needs Through a Community Lens

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ABBREVIATIONS

CYSHCN—children and youth with disabilities and special health care needs

NIDRR—National Institute on Disability and Rehabilitation Research

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Children and youth with disabilities and special health care needs (CYSHCN) represent 13% to 15% of the US population. Their concerns are physical, intellectual, emotional, and social. Frequently, these children and youth contend with multiple, compounded problems. Although the medical, educational, and social systems address the concerns of CYSHCN as high priorities, CYSHCN from traditionally underserved groups continue to face significant barriers to community inclusion. They often do not enjoy the fruits of the new types of health, educational, and social services afforded to other CYSHCN. In this supplement to *Pediatrics*, we present a compilation of articles from researchers, clinicians, policy makers, medical educators, community-based organizations, and parents. Collectively, these authors ask the question, "How can we break through the persistent barriers that keep CYSHCN from underserved groups from benefiting from community inclusion and community-based services?"

Pediatricians and other child-helping professionals are increasingly aware that new approaches including parent-professional partnerships and community-based participatory research can help break down barriers faced by children and families from underserved communities. In the community, new integrated models offer a potential path for improving the health and life experiences of CYSHCN from traditionally underserved communities. In this supplement to *Pediatrics*, we explore some of the new ways that research projects and service-delivery programs are bringing families, communities, and providers together to review data, question assumptions, follow trends, query results, and suggest modifications in direction.

BACKGROUND

In 1999, the Olmstead decision of the US Supreme Court (*Olmstead v L. C. and E. W.*) spotlighted the fact that well after the passage of the Americans With Disabilities Act, people with disabilities were encountering persistent barriers to community integration. Although the Olmstead decision related primarily to the concerns of adults with disabilities, it had important implications for children and adolescents, particularly for traditionally marginalized and minority populations.

As a direct response to the Olmstead decision, the National Institute on Disability and Rehabilitation Research (NIDRR) identified "children and youth with disabilities and special health care needs from traditionally underserved communities" as a group that had been largely bypassed by many disability service reforms and community-inclusion initiatives. In 2005, to study this issue and to stimulate corrective action, the NIDRR released a request for proposals for a national rehabilitation research and training center focused on issues pertinent to these children and youth.

In releasing the request for proposals, the NIDRR stressed its worry that children and youth with disabilities and chronic illness from minority groups, including new immigrants and non-English speakers, are doubly disadvantaged with respect to community-integration service access. Recognizing the increasing diversity of the US population and the disturbing occurrence of health disparities between different racial, ethnic, and linguistic groups, the NIDRR was especially interested in supporting research and training that explicitly targeted underserved groups and aimed to create health equity for CYSHCN. The NIDRR was also interested in sponsoring interventions that actively supported the involvement of community and family members in the design, conduct, and analysis of the research. The main purpose of the NIDRR center solicitation was to generate community-inclusion intervention models and the training materials for their national replication.

A consortium of researchers, clinicians, and community and family organizations joined together as “Opening Doors” to respond to the NIDRR request for proposals. Opening Doors received a 5-year award to establish the Opening Doors National Center. The center was charged with conducting original research and training projects as well as with reviewing the state of research on service delivery for CYSHCN from minority, immigrant, and non-English-speaking backgrounds. The Opening Doors consortium identified 3 priority areas for focus: early identification; community inclusion; and postsecondary education.

A core activity of the Opening Doors Center was having a state-of-the-science conference that highlighted these topics (sponsored by the NIDRR, the Maternal and Child Health Bureau, the HSC Foundation, and the American Academy of Pediatrics). The national

conference took place in Bethesda, Maryland, on November 10 and 11, 2008. The meeting brought together researchers, policy makers, clinicians, families, youth, and leaders from a wide range of community-based organizations. The meeting sessions included research presentations, panel discussions, and workshops, all designed to maximize information-sharing across the diverse range of participants.

RESEARCH FINDINGS AND CHALLENGES

As a follow-up to the Opening Doors state-of-the-science meeting, we have drawn together a group of representative articles that build on the conference findings and discussions. These articles cover basic research, experiences with interventions from the field, and training initiatives. We also present data from the Opening Doors team and the lessons we are learning in the field as well as perspectives from parents, community-based organizations, and policy makers.

To set the stage, we begin the supplement with 3 articles in which the following epidemiologic questions are explored: (1) Who are the CYSHCN? Does the incidence and prevalence of certain conditions vary according to socioeconomic status, race, and/or language? (2) How are children and youth identified as fitting the definition of CYSHCN? Does this process vary depending on family and community background? and (3) What happens to CYSHCN as they grow up? Does access to transitional services vary on the basis of family background, language, and/or socioeconomic status?

To begin answering these questions, in their background literature review, Berry et al¹ document the current prevalence of 14 disabling conditions and confirm the existence of significant health disparities among children

and youth with disabilities. Then, the authors of 2 research articles analyze data from the National Study of Children With Special Health Care Needs to explore several questions about children and youth with disabilities from diverse racial and ethnic backgrounds. Blumberg et al² discuss the provocative finding that on the large national telephone survey of parents, Hispanic parents from non-English-language households were less likely to identify their children as having a disability than were Hispanic parents from English-speaking households. Using the same national telephone survey, Lotstein et al³ document that as young people with disabilities from minority backgrounds grow into late adolescence and young adulthood, their families report a more rapid decline in access to services than do families from majority backgrounds. The authors speculate that the reasons for these results are related to insurance coverage, language difficulties, and the general lack of transition services within all communities.

During the state-of-the-science meeting, the presentations on which these epidemiology articles are based stimulated lively exchanges and debates about such issues as perspective; bias, perceived or real; measurement; reliability; validity; and usefulness of standard research methods. The insights of the community and family members are summarized and presented in 2 response perspectives by community and family members.^{4,5} These reflections help frame the experience of communities and families as they express their hopes and fears about research, model development, and community-based investigation. The community leaders share their experiences of dealing with professionals and public-authority representatives. They discuss the reasons that families may guard personal information and

resist full participation in research. They explain why families may be leery of enrolling in government-sponsored experimental protocols because of previous negative experience with public authorities. They point to the key importance of relationship-building and make it clear that time and consistency are essential factors in the creation of trust between community members and professionals. For research to be meaningful, the respondents point to the critical need to pose questions that are generated by and with the community and for answers of which have relevance in the real-world context.

From the family perspective, Bostic⁵ echoes this sentiment in pointing out how research cannot rest on numbers alone. She argues that numbers must be accompanied by words, but words that are shared and understood by diverse cultures. As she points out, researchers have a culture that is often quite foreign to families and communities.

Both of these perspective pieces^{4,5} speak to a gradual transformation in which researchers, communities, and families are finding ways that each can contribute to work that is mutually reinforcing and that provides information that can inform practice, teaching, and policy.

MODELS FROM THE FIELD

The next set of articles present models from the field that demonstrate how researchers and program developers working with community groups, families, and state-wide community-serving agencies enhance their understanding of facilitators and barriers to disability service provision. These articles address partnership approaches to a variety of disability topics including uptake of special education and health services, community inclusion, and screening/early identification. First, Baker et al⁶

demonstrate the use of community-based participatory research methods. Working with 2 South Asian communities (Hmong and Mien), researchers from the University of California at Davis elicited community input and unearthed a number of deeply and widely held community concerns that helped to explain why few families of children with disabilities were availing themselves of special education and health services.

From their experience at a hospital-based sickle cell project in Minneapolis, Minnesota, Wills et al⁷ report on an intervention to help children with sickle cell disease access developmental and educational services. When the hospital team worked closely with the parents, they found reasons why referrals for developmental services were unsuccessful. They realized that the families had established a deep trust with their unit and that the unit needed to expand its service base to take advantage of the years of parent-professional relationships that had built up. By offering developmental evaluation service as part of a comprehensive package, they found ways to break down barriers that had previously kept families from accessing the full range of services their children with sickle cell disease needed and were entitled to have.

Allen et al⁸ describe the experience of the Illinois chapter of the American Academy of Pediatrics and the Illinois Department of Healthcare and Family Services as they collaborated to improve screening practices throughout Illinois to ensure that families from all sectors, including those who are traditionally underserved, received early-detection services. This model provides practical advice for pediatricians around the country who are interested in working with their chapters to ensure that all children are receiving timely and appropriate de-

velopmental screening as recommended by the American Academy of Pediatrics.

The next 3 articles from the field describe some of the lessons learned as the Opening Doors projects have rolled out. These lessons generally came from actively eliciting and responding to specific, in-depth input from communities, from families, and directly from youth. Glader et al⁹ describe the ways in which the Opening Doors Project Adventure team has worked to engage families, communities, and youth in the design and implementation of a community-based research project on inclusive recreation for children with special health care needs from traditionally underserved communities. Cox et al¹⁰ discuss how the analysis of written comments on the Parents' Evaluation of Developmental Status screening test gives clinicians better insights into a family's interpretation of concepts such as disability and typical development. On the basis of early experience with the Opening Doors Opt4College project, Rosen-Reynoso et al¹¹ present the benefits of a having a flexible approach to the design and early implementation of community intervention research, which allows the research team to take advantage of community and youth ideas and modifications that enhance the research and increase its acceptance and meaningfulness in the community. All 3 of these Opening Doors projects demonstrate the value of attending to the perspectives of the community to provide more meaningful services.

IMPLICATIONS FOR PEDIATRIC TRAINING

Ideally, research such as that presented in this supplement to *Pediatrics* should inform practice and teaching. Although there has been significant recognition in the past decade of the importance of professional-community partnerships

and the advantage of multiple points of view in the design of service programming, there are still many challenges and unresolved practical issues. The final 2 articles of this supplement describe pediatric training initiatives that are taking on the challenge of putting research into practice in the teaching arena. Nazarian et al¹² describe the current state of training about children with special health care needs and family centered care in 5 Massachusetts residency programs. The authors highlight training gaps and offer suggestions for improving the training experience. Patel and O'Hare¹³ look at the ways that both pediatric and internal medicine residents are being prepared to care for youth who are in the process of transition. They describe a new curriculum (WISHES) designed to improve the

residents' abilities to assist CYSHCN through the transition phase. By providing trainees with direct exposure to the challenges faced by CYSHCN and their families, and providing evidence-based guidance on how to address those challenges, the necessary changes in practice can spread far and through generations of clinicians.

SUMMARY AND IMPLICATIONS

Dr Thomas Chapman, the chief executive officer of the HSC Foundation and Dr Fan Tait, associate executive director of the American Academy of Pediatrics have been kind enough to write a summary commentary for this supplement.¹⁴ They review the challenges that are outlined in the research, discuss the promising models, and suggest proactive ways that general pediatricians, subspe-

cialists, community-based organizations and agencies, families and youth, and policy makers can work together to improve opportunities for CYSHCN from traditionally underserved communities.

Along with all the authors, we offer this supplement not to answer all the questions but to engage in a continuing discussion with researchers, clinicians, families, and community groups. At the Opening Doors state-of-the-science conference (www.openingdoorsforyouth.org/sos), we experienced a convergence of commitment. We hope that in some small way the articles in this supplement capture at least a portion of the knowledge exchange, sharing, and power of partnerships exhibited at the conference.

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