

STRENGTHENING FAMILIES OF CHILDREN WITH DEVELOPMENTAL CONCERNS: PARENT PERCEPTIONS OF DEVELOPMENTAL SCREENING AND SERVICES IN HEAD START

Objective: The authors investigated perceptions of parents with children in the Head Start program about the processes of detection and intervention for developmental concerns.

Design: Descriptive, qualitative study.

Setting: A large, urban Head Start agency, operating 14 centers and annually serving more than 1200 predominantly Latino children. During 2008–2009, a collaborative partnership with academicians from UCLA was created to evaluate their model of developmental screening and referrals.

Participants and Procedures: We conducted 5 focus groups with a total of 30 parents of Head Start children with developmental concerns. Parents were asked about where they go for information when they have concerns, how they perceived the developmental screening process and services, and how children and families have changed after being in the Head Start program. Focus groups were recorded, transcribed and translated into English, then coded in ATLAS.ti using the domains above and sorted into themes for analysis.

Results: Parents perceived the screening process as both diagnostically and therapeutically important, with multiple benefits ranging from closer parent-teacher relationships to improved parenting and understanding of developmental interventions. Families focused their discussion on the importance of social-emotional and behavioral development, with school readiness and improved expressive language as important but secondary outcomes.

Conclusions: For families of children with developmental and behavioral risks or concerns, a structured developmental screening process in a preschool setting, such as that provided by Head Start, may serve as a vital gateway for identifying and addressing concerns and promoting social-emotional learning, parent engagement, language development and school readiness. (*Ethn Dis.* 2011;21[Suppl 1]:S1-89–S1-93)

Key Words: Early Childhood Development, Developmental Screening, Early Intervention, Head Start Program, Preschool, Latino Families, Social-Emotional Development

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INTRODUCTION

Developmental and behavioral challenges are common in young children, and the US health care system often does not adequately address parents' concerns. National surveys estimate that 12–17% of children in the United States have developmental, behavioral, or mental health disorders.^{1–3} In addition to these children with diagnosed disorders, parents report concerns about child development or behavior in approximately 30–40% of young children.^{4,5} Children whose parents express concerns but who do not have diagnosed disorders nonetheless score significantly lower on measures of intelligence, behavior and school achievement, so may be more likely ultimately to have difficulties in school.⁶ Despite professional recommendations that pediatricians screen and monitor children for developmental risks and delays,⁷ child health providers do an inadequate job of developmental screening^{8,9} and many young children who are likely eligible for early interventions are not

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receiving services.³ Also, parents have reported that they would like to have information from child health providers about children's development, learning and behavior, and could use more information than they actually receive.¹⁰ These studies illustrate just some of the ways in which the current system of child health services fails to meet the needs of children and families with developmental needs.

For children from racial and ethnic minority or low-income families, unmet needs are even more pronounced. Latino children are less likely than other racial and ethnic groups to have health insurance or a usual source of care.¹¹ Among children with symptoms that might benefit from mental health evaluations and services, the vast majority do not receive services, but Latino children and uninsured children have even greater unmet need compared to other groups.¹² Disparities also exist across physical and developmental domains, with children from low-income families faring worse in overall health status and disproportionately experiencing learning disabilities, speech problems and behavior problems.¹³ This combination of high risk and less access to services makes the need to address developmental and behavioral concerns

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in low-income and minority children an urgent priority.

Due to the disparities in detection and service provision in the healthcare system, early care and education settings such as preschools may prove to be important additional venues for early detection of concerns, referrals to intervention services, and coordination of those services. Previous work by Taveras et al using preschool parent focus groups found that many parents identified their childcare settings as sources of health-related information, and would like more information about topics such as child development, discipline and behavior.¹⁴ Head Start, the federally funded preschool program for low-income families, may serve an important role in providing and coordinating a variety of services for children and families with multiple needs, including nutrition, family social services, and physical, oral and mental health. Head Start programs are required to complete a number of health and developmental screenings for all children within 45 days of enrollment, and also are required to serve children with special needs, who must make up at least 10% of enrolled children.¹⁵ For children with concerns identified during the screening process, Head Start facilitates access to intervention services. This comprehensive role in coordinating health and social services distinguishes Head Start from many other preschool programs and early care settings. A national, ongoing multicenter Head Start study, the Family and Child Experiences Survey (FACES), has enrolled several nationally-representative samples of Head Start children and parents between 1997–2010, to assess Head Start outcomes.¹⁶ Qualitative data from the FACES study include semistructured interviews with a subset of Head Start parents, including parents of children with special developmental needs, but does not include parent perceptions of the developmental screening process.

The study presented here utilized a community-partnered approach to understand parent perceptions of the developmental screening process and intervention services in a large, urban Head Start agency. The study authors worked closely with Head Start staff to identify research questions and priorities for a mutually-beneficial investigation. The study sets out to explore a model process of developmental screening and intervention services in Head Start, which will shed further light on the experiences of Head Start families as we aim to improve early detection of concerns, especially for children and families who are at risk for disparate outcomes in terms of health, mental health, development and educational attainment.

METHODS

The study design and methods were developed in collaboration with Head Start staff and the study authors, using a community-partnered approach.¹⁷ The agency serves more than 1200 children, aged 3–5 years, per year, in 14 different centers. During 2008–2009, 84% of families enrolled were Latino or Hispanic, with 75% of families reporting a primary home language other than English. Head Start parents were sampled by offering participation to all parents whose children had been identified as having developmental or behavioral concerns during the 2008–2009 school year. A total of 30 parents participated in 5 focus groups, ranging in size from 4–10 parents in each group.

The groups were conducted at Head Start centers during September 2009, four groups in Spanish and one in English, all facilitated by the primary author and 1–2 trained bilingual research assistants. Focus group questions were grouped into several domains: 1) where parents go for help regarding concerns about child development; 2) how they perceived the developmental screening process at Head Start; 3) what

services they have received through Head Start as a result of the screening; and 4) the impact Head Start services have had on their children and families.

Focus groups were recorded and transcribed, and coded in ATLAS.ti using the four broad domains identified *a priori* and listed above. Additional, emergent themes were identified and used as additional codes, denoting specific components of the overall processes, including health, mental health, nutrition, social services and parent engagement. Transcripts were analyzed using deductive coding methods based on the domains already identified, and inductive coding for the emergent themes. Quotations related to each code were isolated and sorted, generating lists or piles to determine the most common responses and the range of responses. Preliminary data were presented to community partners for discussion and interpretation as soon as they were available, and are being used to guide our ongoing work, including quality improvement activities for the developmental screening and intervention processes.

RESULTS

Sample Description

Participants were predominantly female (90%), Latino (93%), with an average age of 33 years. The majority were born outside of the United States (83%) and reported speaking Spanish at home (69%). Most parents reported that their children were covered by public health insurance (81% in Medicaid, SCHIP, or a local public program), and 13% reported having private health insurance for their children.

Domains

Parent Help-seeking Regarding Developmental and Behavioral Concerns

When asked about concerns they have or had about their children,

parents confirmed that their concerns were mostly related to speech and language development or to behavior and social-emotional development, including externalizing or disruptive behaviors such as temper tantrums, and also internalizing behaviors such as being shy or timid. Parents reported equally that they go to the child's teacher and to the child's health provider for information about such concerns, but noted a transition toward seeking help more from teachers and less from health providers once their children started school. Other sources of information discussed by parents included books, parent groups, family members, friends, neighbors, the school district, and the internet.

Screening Process

Overall, statements about Head Start's process of screening for concerns were very positive. One of the most common themes that emerged was that the screening process increases parents' awareness about their children's development; "The visit helped me pay more attention to my child. I realized I had not paid attention to the things they were asking about, so they help us pay more attention to see the new things they are learning." Parents often noted that the screening process raised awareness in areas they may not have realized were important; "Sometimes your child grows up and you don't notice if they can jump or if they can stand on one foot...[the screening] helps one notice more about their children in depth not just superficial." Along these same lines, parents noted that the screening process reminded them about needing to follow-up on routine visits to health providers, especially to dentists; "I am good with the medical but with the dental I thought they were too small but they're not too small...it serves as an eye-opener."

In addition to raising awareness about child health and development, many parents noted that doing the

screening as part of a home visit helped the teachers get to know the child in a comfortable environment; "...[teachers] get to know you, your house, where you are coming from." The home visit was also an opportunity for the child and family to get to know the teacher, to be introduced to the staff and curriculum before the start of school; "The home visit helped my son feel more comfortable with the people from the school; before school started he was a little afraid...seeing the teacher outside of school makes them seem more human, less intimidating." Parents also noted that the home visit was an opportunity to express their concerns and receive feedback, describing the visit as a reciprocal exchange between teachers and parents, bringing their knowledge and observations together.

A few parents noted challenges they experienced during the developmental screening. Some of these suggested that parents did not completely understand what the questions were asking, despite being administered in their preferred language, and wondered what the "right" answer was; "Sometimes it is hard to understand the questions. Sometimes we reply and wonder, 'Is my child ok? Was that the right answer?'" Another parent complained, "I didn't know how to answer those questions. I had to think and I didn't know how to answer." Even after noting these challenges, however, parents went on to say that although the questions were sometimes hard to understand, the visits were good because they helped them pay more attention and set goals for their children's learning in school. One parent suggested that a good idea for the future might be to send the questions to parents ahead of time so they can think and observe before having to answer.

Services Received as a Result of the Screening Process

Parents listed many services that their children and families received

through Head Start to address the concerns raised during the screening process. These included services for children such as special education and speech therapy, and also services for parents and other family members such as mental health services or counseling and parenting support groups or classes. One mother of a child with autism described the process of receiving family therapy with her son's father; "Me and my son's father, we got family therapy. When he first got the diagnosis of autism, there was a lot of denial. Now his father understands exactly what he has and what he can do to help him...his dad, after family therapy, he moved back in." Other parents described how Head Start helped to connect them to resources in the community such as food, housing and employment; "I had an economic crisis last year and we needed help with food...they gave us lists for low income housing, and have offered us food and clothes, which is marvelous." Another parent noted that assistance is offered even when parents do not ask for help; "The teacher happened to know there were lay-offs going on at the place I work, so she asked if I needed help."

Impact of Head Start Services on Children and Families

The most common theme to emerge was related to social and emotional development – children becoming more social, more independent, opening up more, helping others, participating more in class, and having improved behavior; "...the children have opened up more. Mine was timid and with the classes he has learned the letters and colors, is more social, he is excellent, has better behavior, is better." The second-most cited impact was enjoyment in watching children learn in general and become more interested in school; "Head Start made her more interested in going to school. She was eager to go to kindergarten." Finally, parents made statements about children learning spe-

cific new skills and knowledge, the most common being new words and increased expressive language, followed by improved nutrition, and learning colors, numbers, shapes, and being able to communicate in both Spanish and English. A number of parents noted that their families were more united, and that they were more engaged in their children's education after participating in Head Start. One father stated this very eloquently; "It's given me more enthusiasm for my son's education, and I think the more enthusiasm we have, the better it is for him...just as our children are developing, so are we."

DISCUSSION

Our findings from these parent focus groups suggest that structured developmental screening in a preschool setting may have a powerful ability to help high-risk families, including the Latino families and families of children with special needs in our sample. An interesting new finding from our work is that parents identify the developmental screening process itself as not only diagnostic but therapeutic—an opportunity to express concerns, to learn, and to engage in a dialogue with varied and sometimes unexpected benefits. Doing the screening in the context of a home

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visit also seems to have therapeutic value, helping the family and the teachers develop closer relationships that both ease the transition from home to school and improve parent-teacher coordination.

Our results are consistent with a family resilience framework previously developed by the Center for the Study of Social Policy, which outlines five key protective factors that high-quality early care and education programs help to promote: parental resilience, social connections, knowledge of parenting and child development, concrete support in times of need, and social and emotional competence in children.¹⁸

While this framework is often used as a model to prevent child abuse and neglect, comments by the parents in our sample illustrate how Head Start helped them build upon these protective factors in the face of poverty and financial stressors, concerns about their children's development and behavior, and family conflicts sparked by a child's autism diagnosis. Even compared to other early care and education programs, Head Start is unique in its emphasis on the whole child and the whole family, including connections to health services and mental health services for parents, for example, which may not always be supported by preschool and childcare settings.

The model of screening and decision making used at this Head Start agency allows for an ongoing process of detecting and addressing concerns, with multiple opportunities to listen to parents, observe children, and bring in various experts into that process to provide support as needed. This investment of time is usually not possible in clinical settings, and the health system has proven itself unable to meet the developmental needs of many children and families, especially low-income, predominantly Spanish-speaking families. Therefore, having supportive community venues with comprehensive services such as Head Start is not only

vitaly important but potentially paradigm-shifting. Interestingly, more than one parent who participated in our groups mentioned that once their child was in preschool, it was the first place they would come to express concerns and ask for help. The families we spoke to all looked to Head Start as an important resource for their children and for themselves.

It is interesting to note that most of the benefits described by families are ones that are not readily captured on the IQ and achievement tests that have historically been used to assess Head Start effectiveness. Parents discussed benefits mostly in terms of social and emotional, rather than academic, development. Even when parents spoke about school readiness, they mentioned skills such as learning letters, numbers, shapes and colors, but they clearly focused on other factors, such as children's ability to pay attention, their eagerness to attend school, their participation in classroom and home activities, and their pro-social behaviors. Also, for children with developmental risks such as speech delay, the processes of evaluation and intervention are intertwined with social, emotional and behavioral considerations – about the home language environment and the parent-child relationship, the relationship between developmental and mental health problems, and the manifestation of developmental delays as behavioral challenges. Parents' perceptions of Head Start services highlight the importance of both children's learning and social-emotional development, and the importance of maintaining a holistic approach when designing and evaluating Head Start programs.

This study has several limitations. First, it represents only a sample of parents at one Head Start agency. Although the agency is very large and represents similar demographics to the wider Los Angeles metropolitan area and school district, it is not nationally representative. Second, the parents who

agreed to participate in the study may not be representative of all Head Start families in this agency or in other agencies. Finally, the perceptions presented here are just from parents, while a range of stakeholders are involved in the process. Similar studies with Head Start and school district staff would be useful, as well as quantitative analyses of results from developmental screening and monitoring tools. Taken together, all of these analyses would provide a more complete picture of the screening and intervention processes in Head Start.

This study also has several strengths. First, it uses a community-partnered approach designed to reflect the priorities of Head Start staff and other stakeholders in the community. Second, these qualitative findings shed light on Head Start's developmental screening process. Although the screening is federally mandated for Head Start agencies nationwide, little is known about how parents perceive the process. It is important to know that developmental screening and a range of services in Head Start help to strengthen vulnerable families. The experiences of these families may help to shape future studies, programs, and policies that may ultimately improve educational, developmental, and long-term health outcomes for high-risk children.

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REFERENCES

1. US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook*. Rockville, Md: US Department of Health and Human Services; 2004.
2. Boyle CA, Decoufle I, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. *Pediatrics*. 1994;93(3):399-403.
3. Rosenberg S, Zhang D, Robinson C. Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*. 2008;121(6):e1503-e1509.
4. Glascoe FP. Parents' concerns about children's development: prescreening technique or screening test? *Pediatrics*. 1997;99:522-528.
5. Child and Adolescent Health Measurement Initiative. *National Survey of Children's Health, 2007*. Data Resource Center on Child and Adolescent Health website. Available at <http://www.nschdata.org>. Last accessed on 01/19/2010.
6. Glascoe FP. Are over-referrals on developmental screening tests really a problem? *Arch Pediatr Adolesc Med*. 2001;155(1):54-59.
7. AAP Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee and Medical Home Initiatives for Children with Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118(1):405-420.
8. Halfon N, Regalado M, Sareen H, et al. Assessing development in the pediatric office. *Pediatrics*. 2004;113(6 Suppl):1926-1933.
9. Glascoe FP, Dworkin PH. Obstacles to effective developmental surveillance: errors in clinical reasoning. *J Dev Behav Pediatr*. 1993;14(5):344-349.
10. Shuster MA, Duan N, Regalado M, Klein DJ. Anticipatory Guidance: what information do parents receive? what information do they want? *Arch Pediatr Adolesc Med*. 2000;154:1191-1198.
11. Flores G, Tomany-Korman SC. Racial and ethnic disparities in medical and dental health, access to care, and use of services in US children. *Pediatrics*. 2008;121(2):e286-298.
12. Kataoka SH, Zhang L, Wells KB. Unmet need for mental health care among US children: Variation by ethnicity and insurance status. *Am J Psychiatry*. 2002;159(9):1548-1555.
13. Larson K, Halfon N. Family income gradients in the health and health care access of US children. *Matern Child Health J*. 2010;14(3):332-342.
14. Taveras E, LaPelle N, Gupta R, Finkelstein J. Planning for health promotion in low-income preschool child care settings: focus groups of parents and child care providers. *Ambul Pediatr*. 2006;6(6):342-346.
15. Head Start Reauthorization: P.L. 110-134 (ACF-IM-HS-08-01). December, 2007.
16. US Department of Health and Human Services, Administration for Children and Families, Office of Planning, Research and Evaluation. *Head Start FACES. A Descriptive Study of Head Start Families: FACES Technical Report I*. Available at: <http://www.acf.hhs.gov/programs/opre/hs/faces/reports>. Last accessed on 01/19/2010.
17. Israel BA, Eng E, Schultz AJ, Parker EA, eds. *Methods in Community-Based Participatory Research for Health*. 1st ed. San Francisco: Jossey-Bass; 2005.
18. Center for the Study of Social Policy. Strengthening Families through Early Care and Education. Available at: <http://www.cssp.org>. Last accessed on 07/23/2010.