

IMPROVING ACCESS TO EARLY IDENTIFICATION AND INTERVENTION

211 LA COUNTY DEVELOPMENTAL SCREENING AND CARE COORDINATION



FAST FACTS

- 4 out of 10 children birth to five years old in California do not have a medical home where a pediatrician can track their health and development, and low-income children are even less likely to have a medical home.³
- Low-income and ethnic-minority children are much less likely to have developmental issues identified early.⁴
- It is possible to identify children with autism spectrum disorders as early as two years of age, yet most children are identified at 4 years of age or later.⁵
- Special education costs for a child with an autism spectrum disorder can cost \$13,000 per year, and specialized behavioral interventions cost much more. Early intervention in the preschool years can reduce the need for costly intervention later on.⁶

Giving Children a Good Start

All children deserve a good start in life. Some children need additional support to develop in a way that is healthy and maximizes their potential for success. Unfortunately many developmental issues are not unearthed until children start school, several years after early intervention services could put them on a typically-developing track. Identifying these children early would give them the best opportunity for life success.

The American Academy of Pediatrics recommends that pediatricians conduct periodic screening for developmental delays during well-child visits of infants and toddlers, including screening for autism.¹ Yet the demands on physicians are great, and even then many children do not have a pediatric medical home that provides on-going monitoring and evaluation. Engaging community agencies in identifying children at risk would increase the number of children with special needs who are identified early and served.² Partnerships between health care providers and community organizations could have a significant impact on health and developmental outcomes by assisting with early identification, supporting parents, and coordinating needed services in a timely manner. One successful example of such a partnership is led by 211 LA County. 211 LA County has employed phone-based developmental screening with real-time screening results, immediate care coordination services, and referral network development as a cost-effective strategy to increase early identification and early intervention with young children in an underserved, low-income, ethnic-minority population.



PARENT STORY

Anthony turned his life around to regain legal custody of his 2½ year old son who had been in foster care for one and a half years. His son's speech delays and behavior problems were troubling. Anthony called 211 LA and took a developmental screening questionnaire that found his son at high risk for potential developmental disability. Anthony was quickly connected to a free comprehensive developmental assessment and a speech therapy program for his son.

"I was eager to learn more about how my son was learning, developing and growing for his age. I know that early intervention makes a difference. 211 LA helped me with information and resources.

**"THANKS TO 211, MY SON
WILL HAVE A CHANCE"**

(Anthony)



"The high rate of risk for developmental delays and [Autism Spectrum Disorders] identified through [211 LA County] screenings, coupled with the fact that one-third of families had pre-existing developmental concerns, signals a critical level of unmet need and underscores the utility of universal screening in this population." ¹⁸



EARLY IDENTIFICATION OF DEVELOPMENTAL DELAYS IN A HIGH RISK POPULATION – 211 LA COUNTY DEVELOPMENTAL SCREENING AND CARE COORDINATION

In September 2009, 211 LA County launched an innovative Developmental Screening and Care Coordination Program.⁷ The screening program uses evidence-based developmental screening tools in the agency's call center to identify young children with potential developmental delays and disabilities including autism. After receiving standard 2-1-1 service, a portion of parent⁸ callers of children birth to five years of age are offered the opportunity to answer questions about their children's development using an on-line developmental screening tool. Developmental and autism screens are delivered by a trained Care Coordinator.⁹ Parents' responses are entered into a web-based form that immediately generates a report of the likelihood that the child has a developmental issue. In the same call, Care Coordinators share the screening results and help families interpret the results.

When screening indicates that a child may be at risk for developmental delay, the Care Coordinator creates an individual care plan and refers the family to appropriate services. Care Coordinators have been able to assist families in obtaining complete evaluations of their children's development, transitioning into early intervention services, and also offer support in finding early childhood program placements or services such as mental health interventions. All children who show indicators on the autism screen are referred to the appropriate California developmental disability regional center, which provides assessments and determines eligibility for early intervention services. Care Coordinators make referrals by conference call including the parents so that parents learn how to request services and advocate for their children. Before ending the phone call, the Care Coordinator secures the parent's agreement with the plan and obtains the parent's commitment to follow through on next steps. Because scoring of the developmental screening tool is conducted using a web-based data entry and scoring system, families receive immediate feedback and can move forward with addressing concerns without awaiting additional appointments.

211 LA County has found that supporting families in navigating services is the key to effective care coordination. Care Coordinators continue to check in until each family no longer requires assistance with the referral process. 211 LA County offers annual follow-up screenings to participants whose children were not found to be at risk for developmental delay, in order to monitor the children's development and support families. Families are also encouraged to maintain contact with their primary health care providers to ensure that children have medical homes where they can receive coordinated care.

During an evaluation period, 70% of parents offered phone screening agreed to participate. A third of participating parents indicated that they had been concerned about their child's development for at least several months.¹⁰ The acceptance rate of parents invited to participate in telephone



screening suggests that this strategy can be an effective method for reaching underserved families. 211 LA County Developmental Screening and Care Coordination offers a replicable model for early detection of developmental issues in high-risk, difficult-to-reach populations. 211 LA County is the first 2-1-1 system in the nation to conduct phone-based, web-supported screening using evidence-based tools. 2-1-1 call centers are located in all 50 states, Washington DC and Puerto Rico. There are 29 counties in California where a 2-1-1 is fully operational, covering 92% of Californians.¹¹

Over 7,000 calls monthly to 211 LA County are from parents or caregivers with children under 5 years old. 211 LA County callers are disproportionately low-income, ethnic-minority, underserved, and without health insurance. Four out of five families have monthly household incomes below \$2,000 and over three-quarters are ethnic-minority: 47% Latino, 30% African-American.

Recommendations

- Include the 211 LA County telephone-based developmental screening and care coordination model as a scalable and cost-effective strategy in implementing the Individuals with Disabilities Education Act (IDEA) comprehensive Child Find system.
- Explore the feasibility of using the 211 LA County model in statewide efforts to strengthen coordination between child welfare services, public health, mental health, and developmental disabilities agencies to screen and provide services to vulnerable children ages 0-5 years.
- Expand reimbursement for developmental screening and care coordination under Medi-Cal (Medicaid) to community-based agencies such as 2-1-1.
- Provide resources to 2-1-1 programs in California to replicate the 211 LA County model and build local community service networks responsive to the needs of families.
- Ensure that state Medi-Cal regulations and private insurance coverages align with new federal requirements under the Affordable Care Act to provide developmental screening.



Screening Through 211 LA County Strengthens “Child Find” Efforts and Coordinated Service

- Children in the population served by 211 LA County— typically families with very low income, homeless or at risk for homelessness, facing domestic violence or other psycho-social issues — are also at extraordinarily high risk for having a developmental delay or a disability.
- Most screening participants reported that their children do not have medical homes or regular well-child medical check-ups where developmental issues might be identified.
- 211 LA County's formal partner network builds cross-disciplinary partnerships that improve integration of care, promote effective communication, and encourage collaboration. As new family needs were identified through the effort, 211 LA County was able to build and extend this network.

Research Supports Universal Developmental Screening

The investment in early identification and treatment is well justified when we consider children identified on the spectrum of autism disorders. Children can be identified by 24 months of age, yet most are not identified until they are 4 years old, and children from low-income and ethnic minority families not until they are 5 years of age or older.¹² Early intervention can positively impact communication and social skills and may reduce the need for expensive interventions later. Behavioral interventions for children identified on the autism spectrum can reach \$40,000 or more per year.¹³

Parents welcome support and guidance. Most parents recognize that the early years are crucial, but many lack important information needed to support their child's development, such as understanding when children reach significant developmental milestones.¹⁴ The Early Periodic Screening, Diagnosis and Treatment program under Medicaid found that parents of eligible children did not understand the purpose of developmental screening, nor were they aware of screening services for which their children are eligible.¹⁵ Families may also encounter barriers in obtaining services once a referral is made.¹⁶ They look to trusted professionals to help them understand development and find support when needed.¹⁷

“The high level of caller interest and willingness to participate [in developmental screening over the telephone] provides evidence of community demand and acceptability.”¹⁹

KEY DEFINITIONS

Developmental surveillance or monitoring refers to the ongoing process of observing a child's development and tracking parents' concerns.

Developmental screening is the process of identifying children who may have a developmental problem or a delay in one or more domains of development, or who are at risk of developmental problems in the future.

Evidence-based screening tools are reliable measures that gather evidence indicating the probability of or potential for a developmental problem, delay, or risk.

Part C is the section of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA) that refers to infants and toddlers, birth to three years of age, who are eligible to receive early intervention services.

Part B is the section of IDEA that refers to children ages 3-21 who are eligible to receive special education services.

Section 619 is the preschool grant available to states for providing educational programs for children ages 3-5 who are eligible to receive special education services.

Child Find: The Individuals with Disabilities Education Act (IDEA) requires that states create a system to "find" children from birth to 18 years of age who may be eligible for services provided under IDEA. Child Find systems must coordinate with other state agencies and systems in efforts to identify children in need of services.

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Endnotes

¹ T The American Academy of Pediatrics recommends that pediatricians conduct developmental surveillance at every well-child visit and complete developmental screening during the 9-, 18- and 30-month visits. Autism screening should be conducted at 18 and 24 months.

² Kaufmann, R. and Hepburn, K. (2007) Early childhood mental health services and supports through a systems approach. In D. Perry, R. Kaufmann, and J. Knitzer (Eds.), *Social and Emotional Health in Early Childhood: Building Bridges Between Services and Systems*. Baltimore, MD: Paul H. Brookes.

³ National Survey of Children's Health. NSCH 2007. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 10/31/12 from www.childhealthdata.org.

⁴ National Survey of Children's Health. NSCH 2007. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 10/31/12 from www.childhealthdata.org.

⁵ Centers for Disease Control and Prevention, Autism Spectrum Disorders: Screening and Diagnosis. May 13, 2010. <http://www.cdc.gov/ncbddd/autism/screening.html>.

⁶ Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities, Autism and Other Developmental Disabilities. Enhancing the Monitoring and Tracking of Autism and Other Developmental Disabilities and Advancing Research into the Risk Factors for these Conditions. April 2, 2012. <http://www.cdc.gov/ncbddd/AboutUs/birthdefects-autism.html>.

⁷ Roux, A.M., Herrera, P., Wold, C.M., Dunkle, M.C., Glascoe, F.P., and Shattuck, P.T. Developmental and autism screening through 2-1-1: Reaching underserved families. *Am J Prev Med* 2012;43 (6S5): S457-S463.

⁸ 211 LA County invited parents and legal guardians of children birth to 5 years to participate in screening. In this brief the term "parent" is used to refer to parents and legal guardians.

⁹ Care Coordinators administered the Parents' Evaluation of Developmental Status (PEDS Online) for all children under age five and the Modified Checklist for Autism in Toddlers (M-CHAT) for children 16-48 months. PEDS and the M-CHAT are short, evidence-based, and accurately detect 70-80% of children with developmental concerns. Information on these screening tools may be found in Glascoe, F.P., Robertshaw, N.S., Camp, M. PEDS Online. Nolensville, TN: PEDSTest.com, LLC, 2012 www.pedstest.com. and Robins, D.L., The Modified Checklist for Autism in Toddlers (M-CHAT). Storrs, CT: Self-published; 1999.

¹⁰ National Survey of Children's Health. NSCH 2007. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 10/31/12 from www.childhealthdata.org.

¹¹ See www.211California.org for counties that have a 2-1-1 service center.

¹² Nationwide Profile from the 2009/10 National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. www.childhealthdata.org.

¹³ Centers for Disease Control and Prevention, Data and Statistics, Autism Spectrum Disorders, March 29, 2012. www.cdc.gov/NCBDDD/autism.

¹⁴ ZERO TO THREE, Parenting infants and toddlers today: Research findings. ZERO TO THREE, 2009, http://www.zerotothree.org/about-us/funded-projects/parenting-resources/final_survey_report_3-11-2010.pdfwww.zerotothree.org.

¹⁵ U.S. General Accounting Office, Medicaid: Stronger Efforts Needed to Ensure Children's Access to Health Screening Services.

¹⁶ Kavanagh, J., Gerdes, M., Sell, K., Jimenez, M., and Guevara, J. An integrated approach to supporting child development. Policy Lab Evidence to Action Brief, Children's Hospital of Philadelphia, Summer 2012. http://policylab.us/images/pdf/policylab_e2a_summer2012_series.pdf

¹⁷ Hebbeler, K., Spiker, D., Bailey, D., et al., Early Intervention for Infants and Toddlers with Disabilities and Their Families: Participants, Services, and Outcomes. Final report of the National Early Intervention Longitudinal Study (NEILS). SRI International, 2007, www.sri.com.

¹⁸ Roux, A.M., et al., op cit.

¹⁹ Roux A.M., et al., ibid.

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211 LA County is dedicated to providing an easy-to-use, caring, professional source of guidance, advocacy, and 24/7 per week access to a comprehensive range of human services to the people of Los Angeles County.

ZERO TO THREE

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ZERO TO THREE is a national, nonprofit organization that informs, trains, and supports professionals, policymakers, and parents in their efforts to promote the health and development of infants and toddlers. ZERO TO THREE is a nonpartisan, research-based resource for federal and state policymakers and advocates on the unique developmental needs of infants and toddlers.

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