

Early Identification of Young Children with Special Health Care Needs

About the Title V Block Grant

The federal Title V Maternal and Child Health (MCH) Block Grant helps states ensure the health of all mother and children. As part of Minnesota's Title V Block Grant activity requirements, the MDH conducts a statewide needs assessment every five years. The needs assessment provides guidance to Title V activities for the next five years by identifying priority issues. This fact sheet describes one of Minnesota's priority issues.

Seriousness of the Issue

The early identification of children with special health through early and continuous screening for developmental or behavioral concerns is a low cost strategy to improve the lives of children and their families, reduce risks and increase optimal health and development as well as prevent the onset of and/or reduce the impact of secondary complications of chronic illness or disability. Screening is defined as a brief procedure, not to determine a diagnosis, but rather to determine whether a child requires further and more comprehensive evaluation/assessment.

Child development is a dynamic and ever changing process and as a result is often hard to measure. Gross motor, fine motor, language, cognitive and adaptive behavior are interrelated and complex. Children develop skills variably and show a new skill inconsistently when mastering it. A single test at one point in time only gives a snapshot of the dynamic process, making periodic screening necessary to detect disabilities as the child grows.¹

Children with mild or emerging delays are often hard to detect because of their variability in mastering developmental skill. Children with more severe problems are more likely to be identified and referred for intervention than those children with milder delays (language impairment, mild mental retardation and learning disabilities etc), whose delay may not be identified until it is more severe.² These milder impairments are associated with poorer health status, higher rates of school failure, in school retention

special education,³ school drop outs, juvenile/adult crime and welfare dependency.

With early recognition of developmental delays, children are more likely to receive early intervention services. Meisels and Shonkoff state that two years of intervention prior to school saves \$30,000 to \$100,000 per child (1990).⁴ A 2005 Rand Labor Research Brief estimates the benefits per child served range from \$1400 to nearly \$240,000 per child or the return to society for every dollar invested extend from \$1.80 to \$17.07.⁵

Nationally 19.5% of children 10 months to 5 years received a standardized screening and 26.4 % were at risk for developmental or behavioral problems. In Minnesota 41.6% of children were screened and 18.6% were at risk for developmental or behavioral issues.⁶

There were 218,110 infants and toddlers (birth to age 3) in Minnesota in 2007.⁷

At early childhood pre-school screening (ECS): approximately 59,375 (mostly 3 and 4 year olds) were screened. New potential problems 22,371 (not children) were identified as in need of further medical or educational assessment/evaluation.

Of the nearly 87,000 infants and toddlers eligible for screening through EPSDT, approximately 18,000 were never screened for developmental or behavioral issues.⁸

In a national survey, substantial variability in surveillance and screening practices were found among pediatricians and family physicians.⁹

The US Maternal and Child Health Bureau has identified early and continuous screening for special health needs for all children as one of the six core outcomes for children with special health care needs.

In the Follow Along Program:

- 3 to 7 % (3970) of the children screened using the Ages and Stages Questionnaire (ASQ), score in the fail range. Many more have concerns



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identified by their families which are addressed by the FAP agencies and may also result in referrals for follow-up including evaluation/assessment.

- 3% (412), down from 5% in 1995, of the children screened using the Ages and Stages Questionnaire Social Emotional (ASQ-SE) score in the fail range. Many more concerns are identified by families completing the SE than the ASQ. Families have many questions about the social emotional development of their children. While the number of children screened using the SE has increased, the number of fails has continued to decline since 1995. Local agencies conclude that this is due to early identification of children at younger ages and the provision of early intervention when problems are milder resulting in fewer concerns (Fails) when children are older.

Evidence-Based Strategies

Early and continuous screening, using a valid reliable screening tool, identifies 70% to 80% of children with developmental disabilities and 80% to 90% of children with mental health problems.¹⁰

Screening is provided in multiple environments including clinics, Head Start, schools, public health, child care, etc. However the screening process is usually to determine eligibility for a specific agency's services or is a one time screening, sporadic or provided only to eligible participants. Some agencies are only doing the social emotional component. In addition, many families are ineligible, unable or unwilling to participate in traditional center based or home visiting screening programs due to the costs, cultural or value differences, lack of time, inability to take time off from work, child care for other children, or families view these programs as invasive or intrusive.

A tracking or monitoring program for children, especially those at risk for developmental, health or mental health issues, identifies children early and assures referral to appropriate intervention services earlier than traditional one time or sporadic screening of children.

Counties with a tracking program have 4 or more per 1000 children eligible for Part C than those counties that do not have a tracking program.¹¹

Follow Along Program (FAP) 2008 Data:

- Since 1995 more than 100,000 infants and toddlers have been enrolled in the FAP. (The program initially started in 1987 but data prior to 1995 is not available in the current database.)
- Regionally 4 to 52 % (average of 12 %) of the birth to three populations in Minnesota were screened for developmental or behavioral concerns through the FAP. (See following chart)

Econ. Dev. Region	Birth to Three Population	FAP Participants 2008	Percent of Birth to Three Population in FAP
1	3425	479	14%
2	3281	285	9%
3	10431	1643	16%
4	7980	4119	52%
5	6432	1474	23%
6	6548	1236	19%
7	17647	2395	14%
8	4832	1507	31%
9	7504	2808	37%
10	20194	4345	22%
11	121696	5234	4%
Statewide	209970	25525	12%

One of the roles public health plays in the community is to link people to needed services. The Follow Along Program assists families in locating services in their communities. This is accomplished in a variety of ways. Information about community resources and events may be included with the developmental questionnaires. When families have a concern about their child or any other member of their family, public health assists that family in locating the resource to address the concern. Examples include financial assistance, mental health assistance, evaluation for developmental concerns, domestic abuse resources, assistance with arranging or paying for medical/dental care, fuel or food assistance, etc.

The most frequently services that public health referred to were: Early Childhood Special Education (ECSE-Part C), Child and Teen Check-up (CTC), Child Care Assistance, Community Education, Dental Services, Early Childhood Family Education (ECFE), Food Shelf, Food Stamps, Fuel Assistance, Head Start, Medical Assistance, MN Family Investment Program (MFIP), Physicians for a Well Child Visit, Public Health Services, and Women Infants and Children (WIC).

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Families were asked to evaluate the Follow-Along program.¹²

1. What do you like about the FAP?
 - 82% Getting child development information.
 - 79% finding out where my child is in development.
 - 70% Finding out what normal development is.
 - 56% getting reassurance about my child's development.
2. What actions have you taken as a result of what you have learned?
 - 65% I am able to assess my child's developmental level.
 - 48% I use toys to teach my child.
 - 40% I am improving my parenting skills.
 - 40% I play more with my child.
 - 38% I talk with my medical provider about health and development concerns.

A March of Dimes/Gallup Poll survey of public perceptions of premature birth suggests that the public does not understand the increased risk for poor health and developmental outcomes sustained by even the most imperiled newborns should they survive.

Current Resources and Capacity

Minnesota Children with Special Health Needs (MCSHN) coordinates follow-up services for children identified through newborn screening to assure diagnostic testing is completed and families of babies with a confirmed newborn screening disorder or hearing loss are connected to supportive local resources. These babies may require early intervention, close medical supervision, and life-long treatment to prevent serious permanent problems or even death. If babies confirmed positive for one of these disorders, either hearing or bloodspot, are identified early and follow treatment protocol, many will have minimal health issues and lead nearly normal lives. MCSHN works closely with designated pediatric specialists including metabolic and genetic specialists, endocrinologists and hematologist, pulmonary specialists, and audiologist throughout the state. Long Term Follow Up assists children and youth with special health needs from birth through 18 years of age. Early identification ensures the best possible outcomes for each child.

The Follow Along Program (FAP) provides periodic tracking and monitoring of the health, development including, social emotional development, of children

birth to three. (More that two thirds of the counties provide universal tracking. The rest provide tracking for children with risk factors.) The FAP also provides anticipatory guidance and education to families about the development of their child and information on healthy development including activities to do with their children to encourage typical development and healthy behaviors.

The FAP is a cooperative arrangement between the MN Department of Health –Children with Special Health Needs Sections and local FAP managing agencies.

The state provides the software, some forms and technical assistance and training. The local agencies usually public health, outreach to their community, enroll children in the program using specially designed software, manage the developmental questionnaires, and provide the follow-up to families. Developmental Questionnaires -Ages and Stages Questionnaires (ASQ'S)¹³ are mailed to the family typically at 4, 8, 12, 16, 20, 24, 30 36 months and sometimes 42 months. Ages and States Questionnaire Social Emotional are mailed to the family typically at 6, 12, 18, 24, 30 and 36 months¹⁴. The parents complete the questionnaire and return it to the local agency for scoring. If the child passes all areas the family receives a letter informing them of the results accompanied by an activity sheet listing age appropriate activities for the parents to do with their children to promote learning and development. Those children who do not pass all areas or whose parents express a concern for their child are contacted to verify the findings, discuss the results and the options available to them for follow and referral including assessment/evaluation. (This follow-up strategy saves money and resources more appropriately used for children in need of assessment or interventions).

In 1995 the FAP costs were:

- \$38 per year per child for direct costs –(personnel, supplies and mileage)
- \$46 per child per year direct plus indirect costs - (overhead, utilities, telephone. computer, managerial costs)
- \$94 per child for direct, indirect and home visiting (home visit=\$78)

In 2005, the FAP costs were:

- \$41.19 per child per year statewide.
- The cost per participant ranged from \$8 per child to \$125 per child per year.
 - 26 agencies reported a range of \$8 to \$30 dollars per child per year,
 - 14 reported a range of \$31 to \$61

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- 7 reported a cost of more than \$62 per year.
- Cost varies depending on the whether or not the agencies include the cost of a home visit as a FAP cost.
- Over 50% of the funds for local agency management are local county dollars.

Local FAP agencies are being encouraged to collaborate with agencies across their county who are also doing screening to minimize duplication and to assure that populations of children are not being missed for screening.

Currently there are 84 counties and 4 reservations participating in the Follow Along Program. The impact of the current budget concerns on the Follow Along Program is uncertain at this point. However, support for it at the local level remains positive. Some agencies may need to cut back from universal to high risk tracking, target specific populations or ages. Some may be forced to eliminate their Follow Along Programs due to lack of funding.

The Follow-Along Program provides a mechanism to assure early and continuous screening through the early childhood years and a method of child find which when combined with other strategies assures a comprehensive child find system.

¹ American Academy of Pediatrics, Committee on Children with Disabilities “Developmental Surveillance and Screening of Infants and Young Children” Pediatrics Vol. 108 No.1 July 2001.

² American Academy of Pediatrics, Committee on Children with Disabilities “Developmental Surveillance and Screening of Infants and Young Children” Pediatrics Vol. 108 No.1 July 2001.

³ Hamilton, Sutton, MD. “Screening for Developmental Delay: Reliable, Easy to use Tools.” The Journal of Family Practice, May 2006 Vol. 55. No. 5.

⁴ Meisels S. J. & Shonkoff, J. P.. Handbook of Early Childhood Intervention. New York: Cambridge University Press, 1990.

⁵ RAND Labor and Population Research Brief, “Proven Benefits of Early Childhood Interventions. 2005 www.rand.org.

⁶ 2007 Survey of Children’s Health

⁷ MDH Center For Health Statistics-Births 2005, 2006, 2007

⁸ Center for Medicaid and Medicare Services. “Annual EPSDT Participation Report.” US Department of Health and Human Services. 2008.

<http://www.cms.hhs.gov/medicaid/epsdt/ep2000.pdf>

⁹ Sices L, Feudtner C, McLaughlin J, Drotar D, Williams M. “How do primary care physicians identify young children with developmental delays? A national survey.” J Dev Behav Pediatr. 2003 Dec;24(6):409-17.

¹⁰ Sturner, *JDBP*. 1991; 12: 51-64.

¹¹ Chan, B., Ohnsorg, F., Infants and Young Children “Issues of Part H Program Access in Minnesota”, 1999: 12(1) 82-90.

¹² Hennepin Co. 2000

¹³ Available from Brookes Publishing

www.brookespublishing.com Asq-3 includes 21 questionnaires covering 1 month through 5 ½ years

¹⁴ Available from Brookes Publishing www.brookespublishing.com Intervals available 6, 12, 18, 24, 30, 36, 48, and 60 months