



Follow Along Annual Report Summary 2008



What is the Follow Along Program?

The FAP provides periodic monitoring and screening of infants and toddlers at risk for health, social emotional or developmental problems to ensure early identification, help, and services. Most of the public health agencies include all children regardless of risk factors.

Why is the Follow Along Program Important For Families?

FAP provides helpful information to families on an on-going basis about how their child is developing and helps them understand the developmental stages of their child. In addition, families are sent age appropriate activities that encourage parents to interact with their children in a positive manner.

Comment from a parent "It is so refreshing to see a focus on prevention and early intervention. You couldn't make participation easier with questionnaires, stamped and addressed envelopes."

What Developmental Questionnaires are Utilized?

- The Ages and Stages Questionnaires 4, 8, 12, 16, 20, 24, 30, 36 months.¹ and sometimes the 42 month.
- The Ages and Stages Questionnaires-Social Emotional 6, 12, 18, 24, 30, 36 months.

What Risk Factors Are Tracked?

- There are variety of Developmental, Medical, Environmental, Prenatal and Social Emotional risk factors.
- The selection and definition of risk factors are determined by local FAP managers.

What Does It Cost?

- 1995 Analysis-\$38-\$46 per child per year.
- 2005 Survey- \$41.19 per child per year

Who Pays for the Follow Along Program?

- State - funded by Part C (IDEA-Individuals with Disabilities Education Act) and Title V.
- Local – Local county funds support over half the cost of the FAP. The balance is funded by a combination of Part C, MCH Block Grants, Collaboratives, LPHG (Local Public Health Grants), and private funds.

How Many Children Participate?

- Since 1995 -101,517 children have participated.
- 2008 - 32,895 children were active at some time during 2008.
 - 25,528 children were birth thru 36 months.
 - 7370 children were 37 thru 60 months.

The story of David

David was enrolled in FAP with no risk factors. He passed the 4 and 8 month ASQ. Upon receipt of the 12 month ASQ the mother called the PHN at home on a weekend. Mom noted that David could not do quite a few things in the areas of gross motor and fine motor. Mom stated that the changes were slow and gradual and she did not notice them until she received the ASQ. The child was diagnosed with muscular dystrophy. He is receiving therapy and PH home visiting.

¹ Other ASQ's are available from Brookes Publishing Company. They are: 6,10,14,18,22,27,30,33,42,48,54,60 months.
www.brookespublishing.com

- The 25,528 children enrolled in the FAP represent about 12 % of Minnesota’s birth to three population. This percentage varies by county and by region.
 - Metro 4%
 - Northwest 25%
 - Northeast 20%
 - Southeast 22%
 - Southwest 29%
 - West Central 26%

The story of Andrew

Andrew passed his 4 month ASQ but mom was concerned about his hearing. She stated that she thought he had a hearing loss. The MDH report said he had passed newborn screening but the hospital chart said he had failed. He had not been referred for an evaluation. The PHN referred to an audiologist. Mom reports that he has an 80% deficit. The PHN has not received the official report yet.

How Many Counties Participate in the Follow Along Program?

- All but Stearns, Faribault and Martin
- Reservations include: Fondulac, Mille Lacs, Grand Portage

Has there been research on the Follow Along Program?

Yes, in 1999 about half the counties were participating in FAP, half were not. Findings included that in counties with the FAP, Part C had 4 or more per 1000 children eligible for Part C than in counties that did not have a FAP.²

Who Are the Children in the Follow Along Program?

- Birth weight – 379 (2%) children had birth weights of less than 1500 grams. Children under 1500 grams are considered by Part C to have a high probability of resulting in a developmental delay and eligible for Part C.
- Gestational Age -1987 children or 8% were less than 36 weeks and 23,488 were 36 weeks or more.
- Race/Ethnicity- 80% are white and 20% are Black, Hispanic, Asian or Native American.

How Many Families Return the Questionnaires?

- Ranges from 88% to 92% with an average of 88%.
- The rate decreases with the age of the child.

How Many Children Fail the ASQ?

- 3-7% fail (Varies with the ASQ interval)

How Many ASQ-SE Screenings are Failed?

- Of the 12,328 screenings in 2008, 412 (3%) were classified as failed.
- This is a drop from the baseline year in 1995 of 5%.
- Some children are referred because of concerns regardless of the scores.

The Story of John

This child's mom was concerned about her child's speech. He scored close to the cutoff on the ASQ. The ECSE and PHN made a joint visit. Child was diagnosed with sleep apnea due to large tonsils. As a result of this sleep apnea he was napping all day. He had his tonsils removed and he will have further assessment including hearing.

² Chan,B., Ohnsborg, F.,”Issues in Part H Access In Minnesota”, Infants and Young Children,1999:12(1) 82-90

What are the Characteristics of Children who Fail an ASQ?

- NICU Graduates
- The more risk factors increases the fail rate
- More boys than girls fail
- Children with developmental risk factors are more likely to fail
- Suspected hearing loss
- Atypical or delayed development
- Gestational age equal to or less than 36 weeks
- Suspected visual impairment
- Suspected speech delay
- Lack of a safe, stable place to live
- Birth weight less than 2500 grams (5lbs 8.2 ozs)
- Apgar score six or less at 5 minutes
- Significant respiratory distress
- Major congenital anomalies or possible syndrome
- Family member with a serious physical disability
- Family member with a serious mental health disability
- History of alcohol use during pregnancy
- Lack of prenatal Care (3 or less visits starting in the 2nd trimester)

What are the Characteristics of Children who Fail an ASQ-SE?

- Environmental risk factors
- Family member with a serious physical disability or mental disability
- Suspected speech delay
- Lack of prenatal Care (3 or less visits starting in the 2nd trimester)
- Lack of a safe stable place to live
- Neonatal seizure
- Chronic illness
- Familial disorder with developmental implications
- Social isolation
- Suspected abuse of alcohol or drugs
- Atypical or delayed development
- Suspected hearing loss
- Major congenital anomalies or possible syndromes
- Difficulty providing care because of disabling medical or mental health condition

Who Refers the Children to the Follow Along Program?

- Varies from county to county
- Statewide, over half come directly from Public Health. In addition, 13% came from the MDH Birth Certificate, 7% from WIC, 6% from the Hospital, 3% from a family, friend or relative, 3% from social services.

The Story of Dakota

Dakota was enrolled in the FAP with no risk factors. He passed the 4 and 12 months ASQ. At 16 months mom wrote "knows several words but doesn't talk much". At 20 months he failed communication and personal social. Mom wrote "uses non verbal ways to get what he wants and doesn't seem to want to learn to talk more". The PHN spoke with the mother and they identified that Dakota had regressed. The mother agreed to a referral and he qualified for Part C and received speech therapy. Mom wished to stay on the FAP and at 24 months he failed communication, personal social and fine motor. After another evaluation he was diagnosed with autism. He is reported to be doing well.

What Services are Children and their Families Referred to from the Follow Along program?

One of the roles public health plays in the community is to link people to need services. The Follow Along Program assists families in locating services in their communities.

The most frequent services that public health referred to directly or gave information about 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).

Summary

The FAP provides a resource to identify children early and assure that children and families receive information on normal child development and are connected to resources they need to assure early intervention and prevention or reduction of disabilities.

The number of children enrolled in the FAP depends on the financial resources available to public health to implement the program. As long as funding remains available, local public health agencies will be able to continue the program on behalf of the community to assure that children and families are linked to the services they need.

2009 Goals

1. Encourage local agencies to implement universal tracking.
2. Encourage local agencies to add more ASQ-SE intervals and increase the number of screenings.
3. Provide technical assistance to local agencies.
4. Facilitate the expansion of the FAP to counties not currently involved, including reservations.
5. Maintain and update the FAP website.
6. Provide training on the FAP software to local users.
7. Develop a password protected website for families and agencies to access to acquire the developmental questionnaires and activity sheets.
8. Promote screening activities in medical homes.
9. Provide training on the developmental questionnaires.
10. Facilitate transition from the ASQ to the ASQ-3.
11. Encourage local agencies to work with local Part C programs to assure that children not eligible are referred to the FAP for ongoing monitoring.
12. Encourage local agencies to have children determined not eligible for Part C referred to the FAP for ongoing follow-up.
13. Encourage referrals to Part C of children born at 1500 grams or less.

The Story of Sarah and James

Sarah failed the 8 month ASQ and James failed the 18 month ASQ in the Communication domain. The PHN made a home visit and discovered a severely depressed mother who was pregnant with her 3rd child. Mom stated that she did not enjoy being a mom anymore. Mom had a doctor's appointment for that afternoon. The PHN called the physician who had no idea that this mother was severely depressed. Mom saw the physician and is under treatment. These children's scores are probably due to mom's depression.

For questions regarding this report or to obtain a full report, contact: Lola Jahnke-MN Dept of Health (651-201-3644)
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