

# **Report on the Early Intervention (Birth to Three) Services Focus Groups**

Prepared for the United Way SOAR Early  
Intervention/Prevention Action Team, a Committee of the King  
County Interagency Coordinating Council

Sponsored by King County  
Developmental Disabilities Division

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## **Introduction**

This is a report to the King County Developmental Disabilities Division and the Early Intervention/Prevention Action Team on information gathered from focus groups and phone interviews held from July 2005 through January 2006. The purpose of the focus groups and interviews was to gather information that will help guide a public education effort to help parents and families access early intervention (birth to three) services earlier.

There were sixty-eight participants organized into eighteen sessions of parents, community organizations, community leaders, public health nurses, physicians, a WIC nurse, and early intervention (birth to three) providers. The following is a list of the sessions and interviews:

- Seven family focus groups
- Three community organization focus groups
- One public health nurse focus group
- Three telephone interviews with Early Intervention (birth to three) providers
- Three telephone interviews with physicians
- One telephone interview with a WIC nurse

The focus group sessions were led by a facilitator and a scribe to record participant responses to a series of seven to ten questions. The questions were designed to elicit comparable information from all of the sessions, although the language was modified to ensure that the questions were relevant given the composition of each group. The sessions lasted approximately two hours. The telephone interviews were conducted by a facilitator who was also taking notes. The interviews lasted about forty-five minutes.

The number of participants and the broad variety of groups generated a large volume of information on their experience with the early intervention (birth to three) service system, barriers for families and their thoughts on how we could increase access and get children into services earlier.

This report begins with a summary and a list of the general themes which are the themes that were shared by most groups; families, community organizations and community leaders, medical community, and early intervention (birth to three) service providers. Each of the group themes are also summarized. The group themes are those that were shared by most of the sessions within the group. This report includes a section on the quantitative analysis from the families group that compares the average age of a child when parents first had some concerns to the average age of their child when they first received services. The report compares the findings from two related studies to the results of the early intervention (birth to three) focus groups and interviews. The report identifies other items that came up

during the sessions or the analysis of the sessions and are worth mentioning. Finally, the report presents the notes from each session by group.

## **Summary**

Participants described a service delivery system that offers tremendous benefits to children birth to three and their families when the connection has been made, but a system that has numerous barriers for families to overcome in order to access the services. Information is difficult to access and fragmented. There are few “trusted allies” or advocates to assist families to navigate the system. Physicians lack information on disabilities and services and take a “wait and see” attitude when addressing a child’s development. Families report experiencing initial denial and fear. There is no universal screening to both identify developmental delays and help reduce the stigma associated with a disability. Cultural barriers including language and a lack of understanding of cultural attitudes related to disability and transportation make it more difficult to get children into services. There are differences in when a child’s developmental issues are identified and when the child begins services depending on whether the child had medical issues or conditions that were identified prenatal or at birth.

Some of the themes from the focus groups and interviews raise issues that can be directly addressed through information and education. Some of the themes raise issues that would more likely be directly addressed by program or policy decisions by state or local government or by service providers. Some themes raise issues that may not be addressed directly through information, education, and program and policy decisions.

## **General Themes**

There were several themes among the groups were shared by most of them. These are general themes.

There is the need for trusted advocates, mentors, or support people to assist families to navigate the systems.

There is an abundance of information available on services, red flags and developmental milestones, but the information is fragmented and difficult for families to access.

Fear and denial by families that their child may have a developmental delay lengthens the referral time.

Concern that physician’s lack knowledge about disabilities, early intervention (birth to three) services, and take a ‘wait and see’ attitude delays referral for services.

There are cultural barriers including language, written materials, and awareness of different cultural attitudes regarding disabilities that interfere with families accessing services.

Early and universal screening is critical to identifying children and eliminating the stigma of disability.

Low income families rely on the WIC (Women, Infant and Children's program) nurses and/or public health nurses for their information.

There is a need for training and information to child care providers, Head Start programs and other places where children are served, including training on screening, and red flags as well as information on early intervention (birth to three) programs.

Transportation is a barrier for some families, including transportation necessary to get to physicians office and transportation to early intervention (birth to three) programs.

## **Group Themes**

The following summarizes themes by each group; families, community organizations and community leaders, medical community, and early intervention (birth to three) service providers.

### **Families**

Many families said that "being an assertive parent" was the key to getting their child services and supports.

Most parents spoke about being "exhausted and overwhelmed" as a result of trying to get good information, navigating systems and understanding procedures, getting to and from therapy sessions, and "surviving from day to day".

Most often families reported finding out about services and support by themselves or from their physician, hospital, or clinic staff. They also said that other support providers, such as staff at WIC nutritional programs, friends or other people helped.

Many parents said that their physician and staff at the hospital or clinic were instrumental in getting them connected to services. Many parents said that family and friends also helped.

Many families indicated that they eventually got the information they needed to make decisions, but at the times they needed it the most they had no idea where to go or who to talk to educate themselves on early intervention (birth-to-three) services.

Many families indicated that their fear and the stigma related to their child having a developmental delay was a barrier to seeking services.

Many families reported that their physicians took a 'wait and see' attitude and lack knowledge about disabilities and early intervention (birth-to-three) services or prioritize medical needs over developmental needs.

Many families indicated there were cultural and language barriers for some people.

There is the need for trusted advocates, mentors, and support people to help families to navigate the systems and provide emotional support.

### Community Organizations and Community Leaders

Community organizations stressed the importance of having a trusted advocate or support person available to families to help them navigate the systems and get the information they need to make decisions.

They believe that early and universal screening of all children would identify developmental delays earlier and also lessen the stigma associated with a developmental delay.

Physicians need to be better educated on disabilities and developmental delay. In addition, community organizations believe that many physicians advocate that parents take a 'wait and see' approach rather than refer children for screening.

Community organizations indicated that finding information on developmental delay and services is difficult for families. While some community organizations are very connected with some early intervention (birth-to-three) programs, others felt they would like to have more information and ongoing connections with the early intervention (birth to three) community.

They believe that child care providers and programs such as Head Start need training on early intervention (birth-to-three) including training on screening and ways to communicate with families regarding their concerns.

Community organizations said that low income families rely on WIC nurses and public health nurses for their information on early intervention (birth to three) services. Not all of the WIC and public health nurses are educated on early intervention (birth-to three) services.

Community organizations identified transportation as a barrier for families, including getting to doctors, clinics, and early intervention (birth to three) services.

The participants from ethnic communities identified several themes common to all families.

Families are largely unaware of early intervention (birth to three) services. They are often in unfamiliar location, away from family and friends and are reluctant to seek help due to such things as cultural or language barriers or difficulty with transportation.

Many resources, such as family support groups, and information available in the community are presented in English, or if translated, are presented with unfamiliar terms. Families rely on other family members, friends, and neighbors, as connectors to local programs, such as WIC or public health nursing, to find 'trusted people.'

### Medical Community

The awareness of early intervention (birth to three) services among medical practitioners varies.

Additional information is needed by families and practitioners on assessment tools that identify red flags, the importance of getting into services early and the importance of all families having information on early intervention (birth to three).

Practitioners believe transportation for families to get to services and therapy is an issue.

Generally, medical personnel have a good experience when they work as a team with early intervention (birth to three) programs, but spoke of wanting more information on how to have a conversation with families about delays and wanting to have it be a two way-street by receiving feedback from early intervention programs after referral has been made.

Practitioners identified a number of barriers including limited time with families, grey areas and a reluctance to alarm parents, system difficulties, services that are not well connected, lack of insurance, parental knowledge and physicians wait and see attitude.

Practitioners believe it is critical that physicians and families understand the importance of early intervention (birth to three) services.

### Early Intervention (Birth to Three) Providers

Providers indicated that physicians that have a relationship with early intervention (birth-to-three) programs are likely to refer families.

Providers indicated that the majority of their referrals come from the medical community.

They believe that the 'wait and see' attitude of physicians delays referral.

Providers said there needs to be an increase in awareness of early intervention (birth-to-three) where children go, such as child care providers and Head Start.

### Quantitative Analysis

Over sixty percent of family members reported that they became aware of their child's development issues as a result of a prenatal diagnosis or at the delivery of a very premature child. There were significant differences between the time that families first became concerned about their child's development and the time their child began to receive services, depending upon whether or not the child had significant medical issues. Children without medical issues were three times as old when their parents first became concerned about their development. Children without medical issues were over twice as old when they first received development services or support. The lag time between the two was fifty percent longer for children without medical issues.

The average age of children when families first became concerned and the average age of their children when they first received services is summarized as follows:

| When            | Age of Child in Months |                        |              |
|-----------------|------------------------|------------------------|--------------|
|                 | With Medical Issues    | Without Medical Issues | All Children |
| First Concerned | 4                      | 15                     | 7            |
| Began Services  | 10                     | 24                     | 15           |
| Difference      | 6                      | 9                      | 8            |

### Other Related Reports

There were two reports that were based on focus groups and interviews with child care providers and Spanish speaking families that had findings that were relevant to this review of early intervention (birth to three) services.

Child Care Provider Screening Tool Study, Child Care Resources, September 30, 2004

Child Care Resources recruited thirty-nine child care providers to participate in focus groups and training on red flags. The following identifies some of the major findings in the report.

- Training on red flags gave child care providers more confidence on identifying developmental delays in children they care for. Many of the early intervention participants suggested that tools that identified red flags for parents and other people in their children’s lives would be helpful in talking with parents about their children.
- Child care providers would like training on ways to approach families with their concerns regarding a child’s development. Many of the early intervention participants advocated additional training on childhood development and disabilities.
- Child care providers believe a physicians “wait and see” attitude contributes to a delay in children receiving services. This belief was a general theme shared by most groups in the early intervention (birth to three) focus groups.
- Child care providers would like more information on early intervention (birth to three) services. This belief was a general theme shared by most groups in the early intervention (birth to three) focus groups.
- Child care providers believe there should be more consideration of cultural issues that affect some family’s ability to access early intervention (birth to three) services. Many of the family and community focus groups spoke about cultural and linguistic barriers for families and children and how cultural beliefs about disabilities can influence a family’s decision to seek help for their children.



- Child care providers did not realize that the Children's Health Access Program (CHAP) is the initial point of entry for all parents in King County. Several early intervention (birth-to-three) focus group participants said that parents, medical practitioners and others need more information about how to access services. They also referred to the system as being fragmented without a single point of entry.

South Faces Child Development Pilot Final Report, United Way of King County and South Faces, June 12, 2005.

There were findings in the Child Development Pilot Final Report that related to the findings of the early intervention (birth-to-three) focus groups.

- Families reported that they compare their child's behavior with siblings or other children in the neighborhood to determine whether their child is developing typically. This was also reported by family early intervention (birth to three) focus groups.
- The report states, "For families with children with special needs, their barriers and challenges to take care of their children were doubled by cultural perceptions and beliefs about disabilities" (pg 17). Cultural barriers were also reported by participants in the family, community, and medical focus groups.
- The report indicates that Latino families preferred to receive information from family, friends, and neighbors. This was also reported by some of the participants in the community leaders' focus group.
- The report concludes that the effective way of reaching out to a linguistically and culturally diverse community is by using community leaders. This is supported by some early intervention focus group participants who emphasized the role of "trusted advocates" in the community to help children and families get connected to services.
- Families report feeling "overwhelmed" with financial burdens, cultural perceptions about disabilities, health care issues, and getting their children to treatment sessions. This was echoed by many families in the early intervention (birth to three) focus groups.

### **Other Items Worthy of Mention**

- The Community Health Access Project (CHAP) was identified by many participants as a "single point of entry" that other participants spoke of needing. There was uncertainty about whether CHAP serves all children.
- Many participants thought there needed to be a different way to refer to early intervention (birth to three) services. "Early intervention" and "birth to three" does not mean anything to many people.

- Children's Hospital is a major source of help to families and a referral source for early intervention (birth-to-three) programs.
- Some families and providers mentioned the lack of respect shown to families when they visit governmental agencies for help.
- Some families mentioned how hard it is to find a doctor if you rely on medical coupons and families may have to travel long distances to see a doctor.
- There is confusion on what services children and families are eligible for, who pays for what, insurance coverage, private pay, etc.
- The WIC nurse reported that fifty percent of all children in Washington State receive services through WIC.
- There was a question among some participants about whether financial considerations influenced whether a child was referred to services, such as whether the family had private insurance.

## **Family Focus Groups**

The following is a summary, themes and session notes from family focus groups held from July 12, 2005 through September 19, 2005. There were seven sessions and thirty-two participants.

The participants were asked eight questions about how they got into the system, who helped, what were the barriers, and what advice would they give to others.

### **Session Summary**

Families are the primary advocates for their children. Families play a key role by being persistent, asking questions, expressing their concerns, and seeking out information that will help them make decision about their child and their child's services.

Families need more information on developmental issues, resources and funding. While families reported eventually getting much of the information they needed they said that initially, when they needed it the most, information was not available, not adequate, and was difficult and time consuming to obtain. Families would like to have a resource guide, a list of early childhood programs and people they can talk to, developmental milestones and red flag information available in physician's office, clinics, hospitals and community centers where families go.

While most parents relied on advice from their physicians, other health care professionals, family and friends, they were told to "wait and see", "give it some time", or "deal with medical issues first" which often resulted in delays in getting the child assessed and into services.

### **Session Themes**

Over sixty percent of session participants reported that they became aware of their child's developmental issues as a result of a prenatal diagnosis, such as Down's syndrome, or at delivery of a very premature child. Many of these parents reported being advised to "focus first on the medical issues" or to "give it [the child's developmental progress] some time".

Of the parents whose children did not have medical issues, most had suspicions about their child's development. Many parents reported that they were aware of differences in the development of their child compared to older siblings or other

children. Many of these parents reported that they were advised to “wait and see” by their family physician or pediatrician. Many parents said that they received similar advice from family or friends.

There were significant differences between when families first became concerned about their child’s development and the time their child began to receive services depending on whether or not the child had significant medical issues. Children without medical issues were three times as old when their parents first became concerned about their development. Children without medical issues were over twice as old when they first received developmental services or support. The lag time between the two was fifty percent longer for children without medical issues.

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Most often families reported finding out about services and support for themselves or from their physician, hospital or clinic staff. They also said that other support providers, such as staff at WIC nutritional program, friends or other people connected to their child helped.

Many parents said that their physician/pediatrician and staff at the hospital or clinic were instrumental in getting them connected to services. Many parents said that family and friends also helped.

Many participants said that “being an assertive parent” was the key to getting their child services and supports.

Nearly all parents said that their lack of information was a significant barrier. They gave examples such as:

- Information about services (viz. what to ask for)
- Not knowing where to start
- Information about publicly funded services
- Insurance coverage
- Developmental norms (e.g. when should I have been concerned)

Many parents said that physicians presented a significant barrier. They gave examples such as:

- Taking a “wait and see” attitude
- Physicians not knowing about disabilities issues and the difficulty of diagnosing some disabilities
- Physicians not knowing about available resources
- Prioritizing medical issues over developmental issues
- Not communicating (e.g. not listening to parents’ concerns or not being “comfortable” discussing developmental issues with parents)

Families reported that their fear and the stigma associated with disabilities was a barrier.

Parents said that there were cultural and language barriers for some people.

Many parents spoke about being “exhausted” and “overwhelmed” as a result of trying to get good information, navigating procedures, getting to and from therapy sessions, and “surviving from day to day”.

Participants said that parents have to be strong and assertive advocates to get the support their child needs. They spoke of being proactive, not accepting “no”, and getting support (i.e. from ARC or support groups).

There is the need for trusted advocates, mentors, and support people to help families to navigate the systems and provide emotional support.

Parents wished that they had information on disabilities and resources sooner. Specifically they said information on specific disabilities, available services (“you have to dig in”, it’s not always clear), parent rights, and the importance of getting developmental services and support as early as possible.

Parents advised other parents that they are their child’s best advocate and they have a responsibility to get the best help available. Specifically, they advised that parents:

- Talk to your pediatrician about your concerns
- Get a diagnosis
- Get your child into services as soon as possible
- Dig for information
- Be persistent
- Trust your instincts.

Parents also advised other parents to appreciate their child for who they are; they are not their diagnosis. Parents should celebrate the positive.

There were several observations from the parent focus groups that did not rise to the level of consideration as a theme, but were noteworthy.

- Families with low income have difficulty finding physicians willing to accept them and are less likely to have a physician or pediatrician note developmental issues in their child and to refer them to services. Families with low income, therefore,

report more often getting referral information from other services providers, such as WIC staff and public health nurses, than through a physician.

- Many families recommended additional training resources focusing on areas such as nutrition, advocacy, insurance and other funding sources, and navigating the system.
- Some families believe that providers of developmental services and supports, such as Children's Hospital and the child development centers withhold information about service options because of their own financial interests.
- Some families wondered what would be available after their child turned three years of age (e.g. "What happens next?").

It should also be noted that many parents spoke of feeling guilty for their child not getting services earlier, even though they acknowledged that they were acting on the recommendations of others that they trusted, such as physicians, family, and friends.

Some parents had specific thoughts about what would be helpful to help families and children get connected to early intervention services and supports. They suggested:

- A resource guide with information on developmental centers and people to talk to such as advocacy organizations, county and state staff, physicians with experience with children with disabilities, and support groups would be helpful.
- Information on developmental milestones and developmental "red flags" that could be available in physician offices, clinics, and community centers would be helpful.
- Team meetings with families before their child leaves the hospital including social workers, physicians, family would be helpful. The meetings could be used to discuss the issues, who can help, funding sources (private insurance, Medicaid, etc.). Families could leave the team meeting with developmental information, milestones, and resources.

## **Session Notes**

Session #1, Children's Therapy Center, Kent

Session Description

The session participants were five parents, three mothers and two fathers, who had children enrolled at the Children's Therapy Center in Kent on July 12, 2005.

## Participant Responses

1. *What was happening with your child that raised questions in your mind about your child's development?*

### Parent #1

- Mother's ten month old started staring at lights. She took him for his twelve month check-up. Dr. said there was no problem, although she felt "something wasn't right".
- At fifteen months, changed pediatrician. Pediatrician advised to "wait and see".
- At eighteen months, started losing language skills and was more physically active. The pediatrician finally referred him to CTC.
- Mother had twins at the time and they had moved twice. There were lots of things going on in the family at that time.
- Twins were premature and had delays from the beginning. They were referred to CTC at seven months because she was already familiar with the program.

### Parents #2 & #3

- This couple's son had a critical reaction to MMR vaccine at fifteen months and was hospitalized. Mother thought son was deaf because he was unresponsive to sounds. Father thought he was autistic because while he had a good bond with his mother, he did not with his father or siblings. Father said, "It was like I was a toy".
- Their son was assessed at sixteen months at Valley Medical Center for speech and motor skills. They said they could not diagnose autism.
- Was evaluated at Swedish and diagnosed with autism. Referred to CTC at two years, participated in group play and therapies.
- His insurance ran out after he turned three, but he was kept in services through a combination of CTC willingness to continue and funding from elementary school.

### Parent #4

- His son was born with significant physical disabilities and a unique condition. Physicians did not know how to support his physical health and no prognosis. Treatment was in the home as physicians were worried about moving his son out of the house (exposure to pathogens, physical injury, etc.). The hospital staff advised the family to read books about physical disabilities. They were left on their own for support. Father said, "We were like the Drs".
- At nine months, son not talking and father suspected a speech delay. Physician was focused on physical health and advised parents to "wait and see". Child referred to CTC at eighteen months.
- Father said that people don't want to admit that their child has delay, but don't want to miss a milestone that "can't be made up later".

Parent #5

- Mother says that she noticed that at six months her son made no eye contact. She had read about "gaze aversion" in autism.
- Physician said there was no problem, but mother still suspected something was wrong, perhaps autism or deafness.
- At two years, her son had a speech delay and was not social. She finally insisted that her son be evaluated and was referred to CTC.
- Mother said her son should have been receiving treatment eighteen months earlier.

2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention services*

Parent #1

- Mother said her son was ten months when she first started to have questions and was eighteen months when he first started receiving services.
- Her twin daughters were born premature and they were in service at seven months.

Parents #2 & #3

- Parents said that their son was fifteen months when they first had questions and was receiving services at two years.

Parent #4

- Father said that his son was nine months old when he first had questions and was receiving services at eighteen months.

Parent #5

- Mother reports that she first had questions at six months and her son received services at two years.

3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- Mother's neighbor had a son who had a speech delay and was receiving services from CTC. She also had worked with children with autism.
- His physician referred him to CTC.



- Her twins received physical therapy from the hospital. PT referred her daughters to UW for an assessment.
- She reports being initially overwhelmed with information. She said, “books don’t cut it – you need a person to go to.”
- Mother said that her husband, family and friends said her suspicions were wrong. Her husband did not want to believe it.
- Mother reports being frustrated and angry with state DDD. She said “I had to call and call and call... to get services”.

#### Parents #2 & #3

- A mutual friend who works at CTC referred them there.
- The family resource coordinator did her job. It took “creative problem solving” with the Kent School District to work out the transition from early intervention services to public school. The family resource coordinator looked out for their son as an individual.
- They said their son was the first student to get funding from the school district.
- They said that people who help are people who can see beyond the regulations and “think on their feet”.
- Parents are the managers of their kids’ lives. Parents are the “#1 people who help”.
- Once parents accept that their child has a disability, then “everyone else believes”.
- School should send staff out that encourages younger siblings to be evaluated.
- They said that people are not even aware of Child Find.
- Parents need more information. Start with the pediatrician. Physicians should have a packet to give to parents.

#### Parent #4

- The father stated that Children’s Hospital gave the parents a resource notebook, but it wasn’t very helpful because it didn’t address the developmental issues they were concerned about. They left the information at the hospital because it was so overwhelming.
- There are gaps in the information. The information is not broad enough to include all kids. Parents have to be “way too involved and resourceful”.
- We needed a person to help us navigate.

- Paying for services was difficult. He said they had to sacrifice their long-term plans to meet the short-term costs of therapy. Families bear a great financial burden.
- They were referred to CHAP program who referred them to the CTC.
- They had to exhaust their benefits through Group Health before they could be eligible for CTC services.
- He said that since his son is attending CTC he is much happier.

Parent #5

- The mother said she signed her son up for numerous generic studies to see if something would suggest he had a disability as she suspected.
- She finally insisted that he be evaluated and was referred to CTC.

4. *Was there any particular thing that helped you get connected to early intervention (birth to three)? If yes, what?*

Parent #1

- Pediatrician finally referred her son to CTC.
- The twins were referred to CTC at seven months by the hospital because she was already familiar with the program.

Parents #2 & #3

- Getting parents and families together and agreeing on what they wanted for their son.

Parent #4

- Like parents #2 & #3. Parents had to be assertive and insist that their issues were addressed.

Parent #5

- Like parents #2, #3, and #4, parents have to work with the pediatricians.
5. *What do you think are the biggest barriers for families trying to access early intervention services and supports?*

All parents

- Getting a "diagnosis". If you don't have a diagnosis you can't get anything.
- Not knowing what to ask for and what's there.

- Parents need to recognize and accept potential problems with the development of their child. Parents need to accept that they need to do something.
  - Parents should realize that it's not their fault. The guilt is tremendous.
  - These issues are for your child's lifetime. It's uncertain as to what the child can do or not do.
  - No one really knows what to do for my child and I can't really plan for the future.
  - What are the services and how can we access them.
  - There is a cultural barrier. It's a challenge to understand advocacy. There is technical jargon, the system has its own language and rules.
  - Parents have an emotional barrier. A grieving process has to happen. After the grieving process, your head clears and then you can think about what you are going to do.
6. *What do you know now about accessing early intervention services and supports that you wish you knew then?*

All parents

- A mother said, "I'm still trying to figure out what information is out there". You have to be prepared to "dig in".
- Parents should always be learning.
- Participants agreed that parents should be prepared to take a major role in their child's life.
- Information is hidden.
- One couple said that once they figured out they needed services, they didn't realize that the waiting lists were so long. They said they wished they knew more about services.

7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention services and supports?*

All parents

- One parent said, "Start calling, get moving and be a squeaky wheel".
- One parent said, "recognition, action, and consistency". She advised, "Be informed and be consistent".
- Another parent said, "Be prepared for the joys, because they're out there once you can see them.

- Another parent said, "Take a step back and see things from [other support people] their perspective. Learn what the rules are in "their world". Establish rapport.
- One parent advised, "Stick to your guns".
- Another parents said "Call the ARC of King County". Another said call your physician for information. Another recommended that people utilize the internet for information.
- One parent advised that "If you are denied services, ask for it in writing".

8. *Do you have any other thoughts you'd like to share?*

All parents

- One parents said, "The window is short and we need you".

Session #2, Encompass, North Bend

Session Description

The session participants were three mothers who had children enrolled at Encompass in North Bend on July 12, 2005.

Participant Responses

1. *What was happening with your child that raised questions in your mind about your child's development?*

Parent #1

- Mother says that her son is the third of four children all born within four and a half years. The family was very busy and relocated twice.
- She thought he was "odd" in that he had unique behaviors. His older sisters talked at eighteen months. Family and friends told her not to worry because he's a boy and his two older siblings "speak for him".
- The family chiropractor was concerned and recommended that they not give him his twelve month MMR.
- At eighteen months, he started to regress. She says her husband was reluctant to pursue services.
- Mother says her son was twenty-nine months when she took him to the pediatrician who referred him to Encompass. She said he was in service within one week.

- Mother says her youngest son has some autistic tendencies. She reports that she'd had no problem getting services from Encompass.

Parent #2

- This mother says that her son has an unspecified genetic disorder with medical issues.
- She says that he had problems in utero. After birth, he could not digest food and now has a feeding tube.
- She says that he stopped growing at six months and was referred from the family practitioner to a pediatrician. After three years the pediatrician told her "he would never get any better".
- She said that her son had "so many specialists that no one had the whole picture". They were more concerned with managing his medical issues that addressing his developmental issues.
- She finally insisted that he be evaluated and get a new pediatrician.
- She was referred to the Boyer Center from DSHS/DDD who referred him to a pediatric specialist. She said that DDD was "quick to respond".
- She said that "there was nobody pulling it all together" for them.

Parent #3

- This mother had twins who were born seven and a half months premature. She was told by the hospital staff to "be patient" with them and that they would likely "catch-up" at about two years.
- They were developing typically. One son had especially good eye contact and they both walked at fifteen months.
- At fifteen months, one son stopped eye contact and appeared to be deaf. His father was not as concerned.
- His pediatrician recommended that they check these things out. She said her son was in service at seventeen months.

2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention services*

Parent #1

- This mother reports that at twelve months they passed on giving him his MMR because of concerns.
- Mother says her son was twenty-nine months when the pediatrician referred him to Encompass.

Parent #2

- Mother says that he had medical issues since birth and stopped growing at 6 months.
- He started services at two years.

Parent #3

- This mother says that she started having concerns at fifteen months.
- She says her son was in service at seventeen months.

3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- Mother says that her pediatrician helped by referring her to ASTAR, a program supporting children with autism and NATTHAN a website for home-schooled children with disabilities. She reports doing research therapies on the internet.
- She says that she especially values Mom's Moment, a monthly mothers group at Encompass and Mommies Can Do, a Christian based organization specializing in neurodevelopmental issues.

Parent #2

- This mother said that after getting connected with DSHS/DDD she was referred to the Boyer Center, the Medicaid CAP waiver, and respite care.
- She said that there was repeated turnover of case manager staff at DDD and a great deal of paperwork.
- She took notes and compiled resource information and steps parents could take to better navigate the system.

Parent #3

- This mother says that her pediatrician referred her to Encompass.
- She says that parents are often in denial even if pediatricians notice something. She says some parents won't seek help.
- She says some parents don't want their children "labeled", although she acknowledges that she is happy to "have labels" because they can lead to needed services.
- This mother says that paying for services after three years is difficult. She says that her family pays \$17,000 per year on services.

- She says it's hard to get parents to participate in groups, such as Mom's Moment. Parents worry about whether they will fit in.
- She says that parents have to "face the fact" that their child has a disability before they are willing to participate in a support group.

4. *Was there any particular thing that helped you get connected to early intervention? If yes, what?*

All Parents

- One mother said that pediatricians got her son connected to services.
- This mother said that she was referred to ARC by an acquaintance at a women's social event. ARC referred her to DSHS/DDD.

5. *What do you think are the biggest barriers for families trying to access early intervention services and supports?*

All Parents

- One mother says that "stereotypes" keep children from services. She says that parents are in denial, especially fathers.
- Another said that the medical community gave them "cover" by focusing on medical issues.
- This mother agrees and says that she has a neighbor whose son appears to be autistic but has only recently gotten him into services.
- One mother said that financial issues are difficult. There is a lack of respite. She cannot get day care for her other children so she can spend time with her son or take him to his therapy sessions.
- This mother says that many necessary supports don't fit into the "funding boxes".
- There are difficulties in finding services. Most parents get their information "word of mouth".
- One mother suggested getting the word out to physicians and other places where children go and broaden the areas in which services are advertised.
- One parent says that they were referred to their current center from their prior center.
- One parent says that their former center never mentioned their current center, even though it was in the town that they lived in.

6. *What do you know now about accessing early intervention (birth to three) services and supports that you wish you knew then?*

All Parents

- One mother wished that she knew that coming to the center was not like enrolling in a DSHS service. She was concerned about her son being on a DSHS "list" that could affect her ability to home-school him.
- Another mother said that there is a stigma that getting services is like getting welfare.
- One parent advised to not wait around while getting assessments scheduled.
- Support groups are not "gloomy" and parents need to laugh and have fun.
- One parent said that early intervention services are about keeping parents healthy along with their children.

7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention (birth to three) services and supports?*

All Parents

- One parent wanted to tell other parents that "It's going to be ok, but you need to be proactive".
- One mother agreed and said "You've got to get busy, get your child evaluated, and get support".
- Another agreed and said, "If your child had a suspicious looking mole, you'd have it checked out right away. You need to do the same if your kids might have other problems."
- One parent said she would clarify for parents that Children's Hospital can give you a diagnosis, but the centers are where you go to get support.
- One mother said that parents should get their child evaluated if you have any questions because if your child needs help now, they may not be able to get it later.
- One parent advised, "You don't have to take therapy if you don't want to".
- One mother said that FEAT has a mentoring program and they should encourage it at centers.
- Another agreed and said that she had greater trust in parents, rather than paid staff because they knew more about what she, as a parent, was going through.
- Another mother agreed and said that parents have more knowledge because "they live it".



- A mother said, "Parents need to let go their fear of not having a perfect child".

8. *Do you have any other thoughts you'd like to share?*

#### All Parents

- There should be a greater effort to let people know about early intervention services, such as physicians and schools.
- There should be brochures developed.
- People should be able to call a toll-free number for information, like a family help line.
- One parent thought that more work in the community could be done to promote early intervention services.
- One mother suggested that promotional material, like organizational banners, should give people a context (e.g. when it started and why) and specific information about services.

#### Session #3, Boyer Children Center, Seattle

##### Session Description

The session participants were five mothers who had children enrolled at the Boyers Children's Center in Seattle on July 21, 2005.

##### Participant Responses

1. *What was happening with your child that raised questions in your mind about your child's development?*

##### Parent #1

- This parent noticed differences in her daughter's peer group. For example, she did not engage in eye contact and was not responding to social interactions like other children.

##### Parent #2

- This mother said that her child's medical issues were predictors of the need to support development.

##### Parents #3

- This mother's child is a twin. She was part of a "twin mom" group at the UW that continued to meet. She noticed that her child was behind other twins in physical development.

- She noticed differences in feeding and didn't realize that it was "low tone"; that his weight was low due to feeding.
- She relates that there was some encouragement to "accept the extremes" [in the twin's development].

Parent #4

- This parent was aware of developmental issues as a result of an injury. Physicians strongly encouraged therapies. The first priority was to keep her alive and focus on medication and immediate care.

Parent #5

- This mother first noticed that her daughter lost skills, such as speech and socialization, and added behaviors like pinching and acting "out of control". Her physician advised her to "give her time". Mother reports still being suspect that something needed to be done.
- After the two months check-up, her doctor said, "let's wait a few more months" when she could be seen with her brother (three months hence). It took her four months to get an assessment.

2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention services*

Parent #1

This mother had questions when her daughter was one and a half years.

She was in service at a little over two years of age.

Parent #2

- Mother says it was about three weeks after her daughter's birth with some therapies at the hospital until discharge at five and a half months.
- She started services at Boyer at five and a half months.

Parent #3

- This mother says her son was nine months old when she first had questions.
- She says that he was in service at one year of age.

Parent #4

- This mother says that her daughter was five weeks when she had her injury and started therapies at Children's Hospital at three months.
- She said she started at the Boyer Center at eight months.

Parent #5

- This mother says she first started having questions when her daughter was one and a half years old.
- She says her daughter was connected with services at two years and four months of age.

3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- Children's Hospital ruled out hearing loss in her daughter and then referred her to services.

Parent #2

- Nurses at Children's Hospital encouraged OT/PT to work on feeding. The neurologist encouraged motorized mobility to encourage socialization.
- A friend who was a speech pathologist suggested speech therapy to address feeding and early language development.
- The Elks Club "Good Works" program provided a therapist that was helpful.
- This mother also has a background in developmental psychology that was helpful.
- This mother adds that there is "no one place" to get all the information that parents need.

Parent #3

- This mother said that her pediatrician referred her to Children's Hospital who then referred them to the Boyer Center after an evaluation.

Parent #4

- This mother said that the physical therapist and neurologist from Children's Hospital recognized that there would likely be a need for services and referred her to the Boyer Center.

Parent #5

- This mother's physician advised her to "give her time [to develop]". She said that an office assistant encouraged her to seek out resources that led her to the Boyer Center.

4. *Was there any particular thing that helped you get connected to early intervention? If yes, what?*

Parent #1

- Children's Hospital referred her daughter to Boyer Center.

Parent #2

- Children's Hospital for the referral and a friend who is a speech pathologist who recommended that she request speech therapy.

Parent #3

- The pediatrician expressed his concerns while family and friends continued to "downplay" her concerns.

Parent #4

- Physical therapist referred by Children's Hospital.

Parent #5

- The office worker at her pediatrician's office advised her to get her concerns checked out.

5. *What do you think are the biggest barriers for families trying to access early intervention services and supports?*

Parent #1

- This mother said that the process and procedures of working through the hospital, the numerous tests and retests, and the waiting periods that delay access to services.

Parent #2

- The lack of knowledge that specific services exist and the lack of details about what are available.
- She said, "If you don't know what to ask for, you may not get it". "You don't know what you don't know".
- The general public needs more education.

Parent #3

- The "red-tape", the process, and the paperwork seemed to delay the focus on the child's needs. She asked, "When are we going to get started?"
- She said that the normal breaks in a center's schedule, like holidays and summer breaks can be frustrating.

- She said that family and friends were barriers as they felt that “waiting [to address her concerns about her son’s development] would be fine”.

Parent #4

- This mother said that learning how to navigate the system and waiting for a program space, appointments, etc. were barriers.
- She added that not knowing what services are available is a barrier.

Parent #5

- This mother said her pediatrician was a barrier. He continued to suggest that she “wait and see” though she still had concerns from her instincts and training as a special education teacher.
- After she pushed her pediatrician, he referred her to Children’s Hospital where there was a four-month wait.
- Her physician’s office assistant suggested that she contact the Boyer Center. This mother said she didn’t think that the pediatrician knew about the center.
- She said that “graduation” from the center puts families back into searching for and coordinating support.
- She said that not realizing she could contact the Boyer Center herself was a barrier.

6. *What do you know now about accessing early intervention (birth to three) services and supports that you wish you knew then?*

Parent #1

- This mother said that she wished she had been able to go to the community resources, other than parents and families, rather than rely on the medical community for direction.

Parent #2

- This mother said that she wished she had known the range of services that are available so that she had been better prepared to know what to ask for.
- She added that she wished she had known that current delays could create possible issues in the future.

Parent #3

- This mother wished that she had access to “emotional support” during the process and support to help her navigate it.

- She said that she realized the value of a peer group that is available and accessible to fight against feeling isolated.
- Parent #5
- This mother said that she wished she'd known that she could have gone elsewhere to get information and services.
- She said that "surviving from day-to-day" makes it difficult to be thinking about what's next and how to get it.

7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention services and supports?*

Parent #1

- This mother advised parents to "trust your instincts".
- She recommended that parents contact the Boyer Center.
- She advised parents to act as support to other parents and focus on the needs of the child.

Parent #2

- This mother suggested that parents be "politely pushy" and to keep asking questions such as "what should we be thinking about" and "what's next".
- She recommended that parents talk with other parents and use them as a resource.
- She advised parents to seek out "typical" experiences and not just focus on disabilities.
- She said that parents should appreciate the child as a child and measure their achievements based on who they are where they've been.
- She said that the child is not his or her disability.

Parent #3

- This parent agreed with parent #1 about trusting your own instincts.
- She added that people should listen to parents and validate their experience.

Parent #5

- This mother advised parents to understand their "rights" within the public education system.

8. *Do you have any other thoughts you'd like to share?*

All Parents

- One mother emphasized the need to keep connecting with people to “uncover” resources. She gave an example of discovering that she could get free diapers for her three year old that was a “little thing” but important.
- She said that convenience was more of a consideration than cost. She said, “It’s the little things [that help]. It’s just one less thing to deal with”.
- Another mother agreed and gave an example of discovering that insurance would cover the cost of a stroller.
- One mother said, “I wished someone had said you can get this”. She posed the question about how parents find out what they are eligible for.

Session #4, Birth To Three Child Development Center, Federal Way

Session Description

The session participants were six parents and one sibling, six mothers and one sister, who had children enrolled at the Birth to Three Center in Federal Way. The session was held on July 21, 2005.

Participant Responses

1. *What was happening with your child that raised questions in your mind about your child's development?*

Parent #1

- Mother had concerns about her son’s speech and eating habits.
- Mother had a difficult delivery requiring suctioning and forceps.
- Child was assessed at six months. The doctor said child was fine, but mother suspected problems.
- Mother was concerned about son not having playmates.
- Mother noticed a friend’s child was doing more than her child.
- Child reassessed at one year and referred to the Birth to Three Developmental Center.

Parent & Sibling #2

- Son had a bladder infection when he was twenty days old and was on IV.
- Family noticed that their son’s arms and fingers were bent.

- Child was referred to the Birth to Three Developmental Center at six or seven months of age.
- Child started at Birth to Three Developmental Center at nine months.

Parent #3

(This mother also has a ten-year old daughter that had received early intervention services from the Birth to Three Developmental Center. Both children had the same pediatrician.)

- Mother had problems during pregnancy with early labor and bleeding. Son was premature, five weeks early, weighting four pounds. Son needed oxygen and did not cry.
- Son cried all the time. Doctor told her to relax, but mom felt right away that there was something wrong.
- Doctor kept saying her son was just a fussy baby, but child was developing slowly and did not sit up until nine months.
- Son was not eating solids at six months. Mom nursed for two years. Son has a feeding tube due to low weight and child's rejection of food.
- Son was finally assessed at thirteen months and referred to the Birth to Three Developmental Center. Child has been at the Birth to Three Developmental Center for thirteen months.
- Son has a sensory integration disorder. Progress has been made on touching things, but child still very sensitive.
- The Birth to Three Developmental Center is working with child on fine motor skills and building strength.
- Son didn't walk until two years of age.

Parent #4

- Son was born with a vascular tumor around his eye.
- Son was put on steroids at three months and got so fat he couldn't move.
- Well Baby checkup showed son was behind, but doctor said it would be okay.
- At son's fifteen month check up the doctor recommended he be assessed.
- Son was twenty-six percent behind in speech and motor skills.
- Son is now twenty-eight months and making amazing progress.
- Birth to Three got him in quickly.



Parent #5

- Mother was having difficulty at the end of her pregnancy and had a c-section. Son was born three weeks early.
- At three months mother noticed that her son could not tolerate being on his stomach and only moved his right side.
- At four months son was referred to the Birth to Three Developmental Center and began receiving home services.
- Mother said her son was given both a MRI, because of the shape of his head was irregular, and a MRA which indicated that he had a vein that was swollen (Vein of Galen). This resulted in his head being out of proportion with his body.
- Child has had difficulty with physical activities, but doing well learning activities.
- Son is in stable condition, and doing well.
- Son is not walking at age two.

Parent #6

- Son was born three weeks early.
- Mother received antibiotics during delivery.
- Son was diagnosed with Down's syndrome.
- Doctor recommended early intervention services at three months.
- Motor skills aren't quite developed, just beginning to walk.
- Mother says son is just beginning to speak at twenty-two months.

2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention (birth to three) services?*

Parent #1

- Mother knew something was wrong but said her son was first assessed at six months, doctor said he was okay, reassessed and referred at twelve months. Received services quickly.

Parent & Sibling #2

- Mother knew something was wrong within first month. Son was referred for early intervention at six or seven month and began receiving services at nine months.

Parent #3

- Mother knew something was wrong because of constant crying. Doctor kept saying just a fussy baby. Son was assessed at thirteen months and was referred to the Birth to Three Developmental Center. Received services quickly.

Parent #4

- Due to son's physical issues it was not until the fifteen month checkup that doctor recommended assessment. The Birth to Three Developmental Center got him in quickly.

Parent #5

- Three months mom noticed son could not tolerate being on stomach.
- Four months began receiving home services from early intervention program.

Parent #6

- Son born with Down's syndrome.
- Began early intervention services at three months.

3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- County Health nurse visited two days after mother and son came home from hospital and recommended mother have son assessed.
- Family Resource Coordinator visited and explained services.
- Doctor referred family to the Birth to Three Developmental Center.

Parent & Sibling #2

- WIC told family about the Birth to Three Developmental Center.
- WIC helped him straighten hand with toys.
- Doctor was concerned that he was not eating.
- Mary Bridge Hospital also helped.

Parent #3

- Nurse practitioner referred her daughter ten years ago.
- Mother brought son to the Birth to Three Developmental Center.

Parent #4

- Child's pediatrician referred family.
- Mother had stopped at Birth to Three Developmental Center to inquiry about child care before her son was referred for services.

Parent #5

- Doctor referred family at four months.
- Twin cousins came to the Birth to Three Developmental Center so family was aware of the program.

Parent #6

- Pediatrician
- Early Intervention (birth to three) program in another county referred family to the Birth to Three Developmental Center when family moved.

4. *Was there any particular thing that helped you get connected to early intervention (birth to three)? If yes, what?*

- Pediatrician – two moms.
- Mary Bridge Hospital – one mom.
- Experience with other kids- one mom.
- Every mom knows when something is wrong. (All moms).
- WIC – one mom.
- Visiting county nurse – one mom.

5. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services and supports?*

All participants

- Parent's not sure what insurance covers.
- Doctor's say everything is fine.
- Parents' don't know early intervention services exist.
- Getting doctors' to listen to you.
- Waiting three months between checkups delays intervention.

- Lack of support from family members.
- Lack of information on services.
- Denial that anything is wrong.
- Language for those families where English is not their first language.
- Parents are not aware of the connection between early intervention (birth to three), King County and State Division of Developmental Disabilities.

6. *What do you know now about accessing early intervention (birth to three) services and supports that you wish you knew then?*

All participants

- Wish pediatricians knew more. Doctors don't know much about disabilities.
- Information on specific disabilities like Down's syndrome.
- Parents' have to work hard to get information that should be available.
- Social workers should be at the hospital to help families with resources and counseling.
- Information packets would be helpful.
- Getting support is easier if child has an easily identified disability.
- More information on parent rights.
- Doctor's should spend more time explaining things to families.
- There should be a way of identifying doctors that have experience with disabilities.

7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention (birth to three) services and supports?*

All participants

- Invite a friend to your home when a therapist is there to help you remember what to do.
- Talk to your pediatrician about your concerns.
- Check things out if you are concerned about anything.
- Go straight to Birth to Three – much easier.

- If you're not satisfied with answers you are being given, find a specialist and don't stop until you get the help you need.
- Get your child into services as fast as you can.
- You are your child's advocate and have responsibility to get the best help available.
- Talk to friends.
- Mom and child should have healthy food.
- Moms' should breastfeed their child.
- Doctors' are going to tell you what you need to do.

8. *Do you have any other thoughts you'd like to share?*

All participants

- Fund nutrition programs.
- Children should be able to get services from different centers.
- What's going to happen after three?

Families would like more training or information on:

- Sensory Integration Disorder
- Insurance Issues
- Nutrition Issues
- Transition from birth to three to next step.

Session #5, Northwest Center, Seattle

Session Description

The session participants were four mothers, three of whom had children that had attended the Northwest Center Child Development Center in Seattle. The session was held on September 12, 2005.

Participant Responses

1. What was happening with your child that raised questions in your mind about your child's development?

Parent #1

- Twins were born premature. Hospital staff talked about possible developmental issues. There was also an older sibling.

Parent #2

- Child was born premature. Parents suspected issues. There were medical issues and within five weeks the child was evaluated for hearing loss.

Parent #3

- Child was born premature. Hospital staff at Children's Hospital referred family to Northwest Center.

Parent #4

- At twelve month doctor's visit mother reported her son had no language. Other kids seemed similar and their mothers' suggested she "wait and see". At fifteen months of age the Pediatrician referred her to services. Mother had no idea what to do unless someone told her what to ask for.

2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention (birth to three) services?*

Parent #1

- Mother indicated that five months after twins were out of the hospital they paid for private therapy for six months. The Occupational Therapist told them about Northwest Center Child Development Center and they began at Northwest Center at eighteen months of age. Mother stated she was given information documents but focused on caring for the twins and did not have the time to search through packets of information for the help they needed. We needed someone to sit down with us at the hospital to tell us in five minutes where we could go for help.

Parent #2

- Before birth due to premature birth. Within two weeks son was seen for hearing problems and evaluated for hearing loss at five weeks..

Parent #3

- Child was four months old when Occupational Therapist at Children's Hospital recommended she contact Northwest Center Child Development Center. Her son started receiving services at five months of age.

Parent #4

- Mother said her Pediatrician raised questions at twelve months and referred her for services at fifteen months. Once referred her son began therapy shortly thereafter.

3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- Therapist at Swedish mentioned birth to three services when twins were eighteen months old after parent's insurance ran out. Mother stated it would have been more helpful to find out earlier, before they were so far in debt.

Parent #2

- Audiologist retested son and referred for services. Parents asked a lot of questions and learned to be patient.

Parent #3

- No one told us. We started receiving in-home supports for our son, but therapy focused on our child and we did not ask questions. I had "no idea what I was doing." It took time to figure out who did what.

Parent #4

- Pediatrician referred us to Swedish, Boyer and Northwest Center. Son was evaluated at Northwest Center and family was told about publicly funded services. Mother said they "totally lucked out" finding public services.

4. *Was there any particular thing that helped you get connected to early intervention (birth to three)? If yes, what?*

Parent #1

- Mother felt the occupational therapist was the one that helped them get connected.

Parent #2

- Parents' asking questions of medical staff and a therapist that referred them for services.

Parent #3

- Occupational Therapist at Children's Hospital.

Parent #4

- "Expensive therapist didn't answer the phone so we went to #3 on our list which was Northwest Center Child Development Center."

5. *What do you think are the biggest barriers for families trying to access early intervention services (birth to three) and supports?*

Parent #1

- Not knowing where to start, not knowing who to talk to.
- When medical issues are the highest priority families don't have time to figure things out.

Parent #2

- Keep pushing through barriers.
- Not knowing where to start or what's available.
- Now uses list serve to pass out phone number to other parents.
- "We were very lucky"

Parent #3

- Not know about services at all. Not knowing what's available.

Parent #4

- We had no money and no idea that something would be available without insurance.
- Not knowing what exists.
- We had no idea anything was wrong.

6. *What do you know now about accessing early intervention (birth to three) services and supports that you wish you knew then?*

Parent #1

- I wish I had known public funded services were available.
- I know where to go now.

Parent #2

- I wish I had known the "top people" or people that could make things happen. A list/directory of people with knowledge about disabilities.

Parent #3

- I wish I had known about the services, what they are and what they do. I received printed material that at the time I "couldn't deal with it."



Parent #4

- I wish I had known that services were available for children without significant disabilities or multiple needs through the government. Plus what exists and who to call.
7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention (birth to three) services and supports?*

Parent #1

- Have your child tested.
- Talk with Pediatrician about what services should be pursued.
- Find out what is available from public funds, doesn't have to come out of your pocket.

Parent #2

- Ask the person diagnosing your child where to start, if they don't know ask Children's Hospital.

Parent #3

- Start with Pediatrician and get another phone number. Ask everyone for another person's number. Don't let them off the line until you get another number.
- Collect cards as you go.
- Just start calling.

Parent #4

- Know that there is stuff out there.
- I still would not know where to tell someone to call
- Dig for information.

8. *Do you have any other thoughts you'd like to share?*

Parent #1

- Someone to talk with you about your issues, what programs are available, what funding is available, etc.
- Information based on your child's needs rather than general information.

- Team meeting at the hospital was available for families with in-home care, but not available to other families.
- Everyone connected with child should sit together at the hospital to figure out what was needed for my child.

Parent #2

- Someone to ask "what do you need at home."
- Having a social worker or Pediatrician come in and talk with you before and after.
- Specifically tailored information regarding my child.

Parent #3

- Having someone sit down for five minutes and say specifically, here are the problems, here are the people that can help, here's what's available through public funding – specific information.

Parent #4

- Information at Doctor's office "showstoppers"/"Red Flags" – Standardized list of things parents should watch for. Information given is "sugar coated."
- List of numbers you would have if you were concerned about something.
- Mom heard different things from different doctors.

Other thoughts:

- It's great they are doing this!
- Pediatricians sometimes don't know if they don't know I don't know.
- Other sources of funding and list of organizations that can help.
- A lot of people don't know where to start. You can use the phone to find out about resources like nurses hot line.
- Insurance agents don't know what's covered.
- Another insurance company assigned a "caseworker."
- Having access to information, like nutritionist, and other people.
- Training that would be helpful - furnish child care as it is difficult to find:
  - If no classes then having a resource person you could call.
  - Advocacy (What level of insistence is best).
  - Insurance expert.
  - Nutrition.
  - A "point person" from King County Early Intervention.

- Information, especially in the beginning.

## Session #6, Kindering Center, Bellevue

### Session Description

The session participants were four parents who had children enrolled at the Kindering in Bellevue. The session was held on September 14, 2005.

### Participant Responses

1. *What was happening with your child that raised questions in your mind about your child's development?*

#### Parent #1

- This foster parent had supported many children over the years and had two children in early intervention services recently. One child was hospitalized for profound neglect and came to her with a referral to the Kindering Center.
- Her second child was born prematurely and she noticed that he had developmental delays. She enrolled him at Kindering Center because of her experience with the center with her other children.

#### Parent #2

- This mother of twins knew through an ultrasound that one of her children was disabled. She spoke with a high-risk pregnancy specialist and contacted the Kindering Center herself.
- She was able to get him into services within about four weeks. She said that she was able to get her child into services "much sooner" than if she went through her physician.

#### Parent #3

- This parent said he was her first child and she didn't know much about early child development services although she is a nurse.
- She said that she noticed that her child cried more than other children and slept only intermittently.
- She said her son referred by her physician to the University of Washington after his two-year well baby check. She said her physician "mentioned" the Kindering Center. She said that she "got no help" at the University. Her son was assessed at Kindering six months later and was diagnosed by CHDD.
- She said that her younger daughter was "low tone" at birth and she brought her to Kindering Center at six months because she "knew more than she did with her first child".

Parent #4

- This parent says that she didn't notice any problems with her son at the time and that her pediatrician pointed out some delays at about eighteen months.
- She said that, in hindsight, she could now identify problems at about seven or eight months.
- She agreed with the pediatrician to wait another month. At nineteen months he was referred to the Kindering Center.
- She said that the family resource coordinator sent her for a diagnosis for her son when he was about twenty-three months old.

2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention (birth to three) services*

Parent #3

Her child was two years old when she had concerns and he was two and a half when he was diagnosed and began services, three months of which was due to the summer schedule (center is closed during the summer months).

Parent #2

She knew prior to gestation that there would be issues and was in services at the age of one month.

Parent #1

- This foster parent's one child came to them at nineteen months of age and had been diagnosed with fetal alcohol syndrome and was in service one month later.
- Her second child was born prematurely and was evaluated at CHDD at four and a half months, though she was told that there was "nothing obvious". She added that the actual results of the assessment would have resulted in him being eligible for services, but that she was not informed of the actual results.
- She got this child into the Kindering Center at six and a half months through the Cherish foster care program when her son was assessed again.

Parent #4

This mother says that her pediatrician shared her concerns when her son was about eighteen months old. He was evaluated at about twenty-three months and was in service one month later.

3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- The Children's Hospital and the high-risk program specialist and the Cherish foster child program.

Parent #2

- The pediatrician and the high-risk pregnancy specialist

Parent #3

- The pediatrician. This mother also reports having some contact with another child with a disability.

Parent #4

- Child's pediatrician referred for the assessment and the family resource specialist helped them understand the treatment options.

4. *Was there any particular thing that helped you get connected to early intervention (birth to three) services? If yes, what?*

Parent #3

- This mother said that was nothing in particular that helped her get connected. She said that she was "in a fog" for two days and that it took several "gentle" influences to help her seek services.

Parent #4

- This mother reported that there also were several influences, but that she realized that there was an issue.

Parent #2

- This mother said that she had been reading about her premature twin's conditions. She also said that she heard about services from friends and other families who participated in a mother's group.

Parent #1

- This mother says that the physician had referral papers and strongly encouraged her to seek services.
- She also adds that the Cherish program was instrumental.

5. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services and supports?*

All participants

- Not being aware of birth-to-three programs. This thought was echoed by a second mother.
- The lack of transportation to and from appointments, especially for families with low income.
- The time lag between when you've identified the need for services and getting the evaluation done.
- One mother cited the "pure exhaustion" from the multiple appointments. She added that in-home services were very helpful.
- Knowing when it is time to be concerned. There is a "backlash" against "hyper-parenting". It would be helpful to have some objective measures that could act like "red flags".
- Professionals are afraid to talk with parents. This sentiment was shared by several participants.
- Behavioral challenges are more difficult to diagnose. There is a lack of knowledge on the part of the professionals about issues that may be serious.
- Our society, pediatricians, etc. wants to "play it down" when it comes to dealing with developmental issues whereas medical issues are dealt with "right away".
- There is a stigma associated with what some view developmental issues as "the very worst thing".

6. *What do you know now about accessing early intervention (birth to three) services and supports that you wish you knew then?*

All participants

- Parents have to work at getting services. You have to know how to ask the right questions.
- Another mother added that there is no one who will volunteer all the information.
- This mother thought that early intervention services, like WIC were for "someone else". She said that she didn't know that children can be enrolled in public school at the age of three. She didn't know that there were publicly funded services were available.
- The system is not well coordinated. One part of it doesn't know what the other parts are doing.
- There is no one place to get everything, such as information.

- The Community Health Access Program was not aware of the developmental issues of foster children. They didn't know that people could go to the Kindering Center or the Cherish program.
  - One mother said that she wasn't aware that she needed to go through her child's pediatrician. She went to the Kindering Center first.
  - One parent said she wished she had known that the rules vary by school district.
  - One parent said that she started getting on waiting lists and making phone calls.
7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention (birth to three) services and supports?*

All participants

- Be proactive and persistent.
- Join a support group.
- Know the system before you "get to it".
- One mother said that she needed a "mentor", someone to sit down with. She said that some people can do the research on their own and people like her need someone there with her such as another parent.
- Another mother said that the support needs to be positive, however. Mentors need to be sensitive.
- Family resource coordinators are a huge help. This mother says that her FRC suggested that she start getting on lists.
- It would be helpful to have a guide or a pamphlet with a step-by-step list of what you should do, the categories of professionals and what they do, and a glossary of terms.
- A book of lists of resources would be helpful. One mother said that she was not aware of publicly funded services.
- After two and a half years of age, support for the child becomes disjointed. Schools do not provide education and supported and are not educated on early intervention services themselves.
- School aides need more training. Parents often do the training themselves.
- One mother said she'd like to see the needs of foster children better addressed. Foster children are especially at risk of developmental delays because of the abuse and neglect they experienced from their birth family.
- Parents need a "introduction to the system" training.

- Parents need more information about their choices, for example publicly and privately funded services.
- Pediatricians play a pivotal role and should have a social worker available to answer developmental questions like hospitals have rather than have parents call the physician.

8. *Do you have any other thoughts you'd like to share?*

All participants

- Parents should have access to the best and most recent information about their child's specific developmental issue. Parents need to know, what is the "right path?"
- One mother said that she is frustrated at not knowing what services are available. She says that she "stumbled" into important services "by accident".
- One mother suggested that the county create a web site data base that has current information about the array of services available in this county. Another mother agreed with this idea.
- Another mother added that while her physician has a web site with information health information, there is nothing about child development.
- One mother suggested a help-line like the public health nurses help line that could help with developmental issues.

Session #7, Wonderland, Shoreline

Session Description

The session participants were three mothers and one father, two of whom had children that had attended the Wonderland Child Development Center in Seattle. The session was held on September 19, 2005.

Participant Responses

1. *What was happening with your child that raised questions in your mind about your child's development?*

Parent #1

- Mother felt there was something wrong at twenty-one months. Parents have to use a head lock to brush teeth. Son has delays in speech and social skills. A friend who is a speech therapist suggested mother contact Boyer Child Development Center. The doctor didn't notice any delays.



Parent #2

- Mother felt her daughter was active to an extreme level. Did not like being held and cuddled. Mother said child was wearing her out. Nurse from WIC mentioned Wonderland. Daughter was referred at twelve months and started receiving services at 14 months.

Parents #3 & 4

- Parents thought son was on the right track and felt he didn't do some things because his older brother did everything for him. Their older son had delays so when staff at Sorenson School suggested they have younger child assessed by Wonderland Child Development Center they contacted the center.
2. *How old was your child when you first had these questions? How old was your child when they got connected to early intervention (birth to three) services*

Parent #1

- Mother indicated that her son was twenty-two months when he was diagnosed. He began receiving services from Boyer Child Development Center at twenty-four months of age.

Parent #2

- Mother stated her daughter was assessed at twelve months and began receiving services from Wonderland at fourteen months.

Parents #3 & 4

- Parents indicated that their oldest child was three years old when he began receiving services. Their youngest child was eighteen months old when he began receiving services at Wonderland.
3. *How did you find out about services and supports that could help your child's development? Who helped and how?*

Parent #1

- Mother had friends in the medical community and a physical therapist suggested she contact Boyer Child Development Center. It was helpful to get a diagnosis. Child was a year or so when he was diagnosed with Autism. Mom was able to use internet to get more information after she had a diagnosis.

Parent #2

- WIC nurse listened to mother talk about her concerns and suggested she contact Wonderland.

Parents #3 & 4

- WIC nurse helped when they moved to King County and told them about resources. Parents moved from Snohomish County and felt the nurse in Snohomish did not have information on the resources like the nurse in King County had.
4. *Was there any particular thing that helped you get connected to early intervention (birth to three) services? If yes, what?*

Parent #1

- Mother felt the Resource Coordinator at Boyer who is the liaison with insurance companies and other services helped her navigate the systems.

Parent #2

- Mother felt the WIC nurse that listened and researched information for her helped her get what she needed.

Parent #3 & 4

- Staff from Sorenson School suggested they have their youngest son assessed. Their older child was in the system and attending Sorenson.
5. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services and supports?*

Parent #1

- Mother said her lack of knowledge about services.
- Parents need an early intervention check list.
- Parents need to have a resource guide.
- The checklist and resource guide should be available at hospitals, doctors' offices, community centers, anywhere families go.
- Information should be handed out at wellness checkups.

Parent #2

- Information should be widely published.
- Insurance restrictions.
- Government funding.
- Lack of knowledge.

Parent #3 & 4

- Insurance issues.
- DSHS coupons – Many doctors' don't take coupons. Families have to drive long distances to doctors that will accept coupons.
- Seems like everyone guards their information. It is like pulling teeth to get information.
- Lack of support groups.

6. *What do you know now about accessing early intervention (birth to three) services and supports that you wish you knew then?*

Parent #1

- I wish I had known places to call like the ARC.
- I wish I had known the resources that are out there.
- I had to convince the doctor that my son needed services.
- You need to be assertive.

Parent #2

- I wish I had the information to know that my daughter might have delays.

Parent #3 & 4

- We know more about the services that are available now. We wish we had know that so our first son could have received services prior to age three.

7. *What advice would you give to parents that have recently learned that their child has a delay about accessing early intervention (birth to three) services and supports?*

Parent #1

- Call the ARC.
- Talk with other parents of kids with delays.
- Be proactive – It's like having another full time job.

Parent #2

- Parents should have support so they can be better parents. So you won't feel so weird and have a place to vent.

Parents #3 & 4

- Go to a specialist.
- Ask other parents. Parents know better.
- You need a checklist when you leave the hospital.
- Don't give up until you find the right person.
- Eventually you will break through.
- System is built to miss people.
- Lots of people don't have the time so they give up.
- System has to be made easier.

8. *Do you have any other thoughts you'd like to share?*

Parent #1

- Pediatricians, doctors, nurses need to be trained on disabilities.

Parent #2

- Publications with a range of normal development.

Parents #3 & 4

- Range of milestones would help.

## **Community Organizations and Community Leaders**

The following are session summaries, themes and notes from focus groups with community leaders, Eastside FACES, and the Friends of Youth.

### **Community Leaders**

The following is a summary, themes and session notes from a focus group held on January 24, 2006. There were eleven participants, six family members and five social service advocates and staff. Participants were from the Latino, African-American, and Asian-Pacific Islander communities.

The participants were asked seven questions about how families get referred for services, barriers and ways to improve access.

### **Session Summary**

The participants reported the same issues as those from other family and provider groups and in addition reported challenges with culturally-specific attitudes about disabilities, language barriers, and difficulty with transportation. Participants agreed that resources and information needed to be presented in a culturally appropriate way, by "trusted people" in a language that is accessible to families could help increase access to early intervention and other support systems.

### **Session Themes**

Families are largely unaware of early intervention (birth to three) services. Families are often in an unfamiliar location, away from family and friends and are reluctant to seek help due to such things as cultural or language barriers or difficulty with transportation.

Many resources, such as family support groups and information available in the community are presented in English, or if translated, are presented with unfamiliar terms. Families rely on other family members, friends, and neighbors, as connectors to local programs, such as WIC or public health nursing, to find "trusted people".

Participants suggested culturally and linguistically competent resources, like family support workers, and public education material in ethnic newspapers would help get the word out about early interventions (birth to three) services.

## Session Notes

1. *In your experience, what do families do and whom do they turn to when they have questions about their child's development? (Example, slow to sit up, crawl, walk, talk or other delays)*

### Participant #1

- A child might be exhibiting the behavior of autism, but the family doesn't believe that the child has delay. Therefore, they don't want to seek help at all.

### Participant #2

- I was friends with a couple a longtime ago. Both did not speak English. Their first child was born with cleft palate. The way she behaved was like back home how others did. They did not want to show their baby to others because of the embarrassment. They were embarrassed to bring the baby out. In my hometown, people who have children with developmental disabilities won't go to the public. I want to help her. I have a child with a developmental disability. But I showed her around in my hometown.

### Participant #4

- In Mexico the most important thing is to admit that our children have developmental disabilities, so we can get help. In the United States people are very accepting but not in Mexico. Here we see children at the park or in public.

### Participant #6

- For some families, it will take some time for them to realize or to admit the issues or concerns. Some families might fear the delay of the child, so they don't go to see a doctor about the child's issues.
- When I first came here, I didn't know the system. My child has speech delay. I was really worried about it. I don't have any relatives around. In addition, in Mexico, we did not know anything about early intervention. The culture is very different than here.
- Taking time from work to ask a physician or accessing other services was very difficult and challenging to me.
- Some times people are afraid that they would be expected to pay or otherwise give something back for the services they provided to us.

### Participant #7

- When I first came here, I did not know the culture and language. I knew my child had a disability.
- Taking time from struggling with a child is challenging. My son's delay was different.

- I had to check with my family first. My family said, "don't worry". Many people reassured me he was okay. It delayed all the early intervention services for my son.
- Because we had to learn the culture, system, and languages, we had to spend extra time to access services.
- A couple of years ago, I took my son to see the doctor. He has some behavior issues. He might scream or yell. People in public did not realize that my son has disabilities. A woman scolded us about his misbehavior. My husband was really embarrassed, so ever since, he always wanted to keep my son at home.
- I want to take my son in public. I would explain to people when my son is misbehaving. I think that as parents, we need to educate the public more about the disabilities issues.

Participant #8

- This is my fifteenth year working with families. I have to continue to remind parents and the communities to include children with developmental disabilities and their families. We don't hear about developmental disabilities issues in the communities or at the table.

Participant #9

- Physicians. For Cambodian families, because of the cultural perspectives regarding disabilities, many families deny the fact that the child has a delay. Families won't seek help because of the cultural stigma.
- I got help from a worker. She gave me a book about child development. That helped me a lot. Now I always go to the library to get information.

Participant #10

- Families, friends and neighbors. We don't have any relatives here, for us Koreans, living isolated, sometimes we don't ask for physician's advice although we might suspect that our children have some differences from others.
- I think that society needs to know more about disabilities. It's not only the parents' responsibility to educate others.

Participant #11

- Some cultural perspectives regarding developmental delay may actually delay the family from seeking help.

2. *What supports are available in your communities that help families that have a child with a developmental disability or delay?*

Participant #2

- WIC nurses are the ones who helped me. Some of my friends went to WIC because they don't know how to ask questions and they were not getting what they needed.

Participant #3

- It helps if there is a list of bilingual staff who will know the services that we can access.

Participant #5

- Before my son attended Head Start, I did not know anything about that. My family support person was the one who helped me and showed me all the resources. Without her, I wouldn't have known all the services available to me. Therefore, I know it is the "trusted people" who helped me. And I don't have any language barriers. It is who you know.

Participant #6

- On top of everything, if your literacy skills are not there, even with translation available, the information is still useless.
- In addition, the terms used in the information that is available is hard to understand. What if families are working and busy, what can they do about it?

Participant #7

- In my case, WIC did not understand developmental disabilities services. Asian Counseling and Referral Services did not know much about employment services for people with disabilities. We need to have people who know about the services to the particular ethnic group. The first time I worked with a family, they told me that was the first time in seven years for them to know about employment services.

Participant #8

- I did not know that Public Health has nurses who would come out to visit us. That's about "who you ask and how you ask." When I was in the hospital, the nurse told me that she could come out to visit me. I spent all of our resources to help my son, the hospital did not tell us about early intervention, so we had to pay for all the services.
- The nurse that worked for a long time knows the services. I don't have any language barriers either.

3. *Are you aware of the supports available to families through child development centers throughout King County? (These supports are sometimes referred to as early intervention or birth to three services)*



#### All Participants

- All participants shaking their heads in agreement that they did not know much about it.

#### Participant #10

- If we don't need it, we won't think about it.

4. *Since a delay in getting a child into services might mean missing the opportunity for intervention when the brain is developing most rapidly, what is the best way to get information about birth to three services to families that have a child with a developmental disability? (Examples, brochures, face to face, direct mailing, churches, community centers, other places families gather)*

#### Participant #1

- Family support workers. Sometimes, some bilingual workers might treat families who lack English skills differently. Once the worker knew I speak English, she changed her attitude.
- Making Connections are planning to connect community members together. They will be able to go to one place and refer them to other services. It's my vision to see the community connected.

#### Participant #2

- My husband doesn't help me much with raising children, so I had to do everything. In some cultures, men and women have different roles. Men don't do things related to child issues.

#### Participant #4

- I had a similar experience. My son did not speak when he was three. One of the WIC staff asked my son questions, he could not answer. So, the staff said we needed to get help. She referred to a telephone number but everything was in English. So she called back to WIC and asked WIC staff to call her. Finally I was able to receive the services.
- One problem is that I don't drive and don't get much support from my husband. Going places was a big challenging to me. It was a huge task. I need to write down everything and navigate it first.
- I later got connected with Head Start. I told the teacher about my concerns about my son. She told me about Child Find and the need to send my child to a special school. I would do anything for my son, but I can't drive. Transportation is one of the biggest challenges.
- I talked to Child Find about the transportation issues. I can't get to them. Therefore, my son is receiving services from Head Start.

#### Participant #5

- Bilingual staff need to be educated on how to be sensitive. It's not the language it is the attitude. We need to have community members to be the resources themselves. They need to be connected.

#### Participant #7

- Advertising in physician's offices. In community newspapers of their languages. In my community, people like to read our ethnic newspapers.
- When my son was served by Children's Hospital, the doctor did not know anything about early intervention so we did not know about early intervention. He only mentioned the Kindering Center in Bellevue. I was connected to early intervention through the Kindering Center
- When we found out about his diagnosis, we were overwhelmed. There needs to be a system for the physician to tell families about it.
- In addition, I had to fill out forms twice to get early intervention services. Later when the outreach staff got connected with me I found out that my applications for developmental disability services were all lost. That delayed services for my son for two years.
- My early intervention experiences are not all positive. When he got connected with early intervention, he was two and a half years old and only had six months of services left. By the time the service started, he only had two months left.
- The worker who came to provide services to my son at home did not explain the services. She only asked me to sign the paper and pay her at a higher hourly rate. If it was explained to me I might have been able to find someone to perform the work at lower rate. So I might have been able to provide more services to my son when he needed them the most.
- Now I would tell all parents to get the services right away. Don't wait. You will never know if the services would be available again.
- I had to quit my job to transport my son to early intervention services.
- I went to a support group. A lot of times, I felt lonely and did not know what was going on because of my low English skills. I went through a lot of hardship because of the language barrier. I did not drive on the freeway before my son's diagnosis. I was forced to drive because I had to take him around to see specialists.
- Some of the early intervention services are not provided in the communities, that creates the hardships for families. Child care is another huge issue. They don't want to take care of my son for safety reasons. We then have to keep him at home.

Participant #6

- Most support groups are conducted in English. I want to connect with parents who speak the same language and share a similar cultural with me. Without language supports, it is difficult for many parents.
5. *What do you think are the biggest barriers for a family needing early intervention (birth to three) services for their child with a disability?*

All Participants

- Transportation. Just knowing how to get around.
  - Spouses are not enough help. It may be cultural. Men make decisions and bring home the money, but women are in charge of the children.
  - Schools do not tell people what is available. It's as if they talk about it, they will have to pay for it.
  - Child care for children with disabilities and for siblings during therapy sessions is very expensive.
  - Family supports, like groups, that are only in English.
6. *What are three things that you think could make it easier for families to participate in early intervention (birth to three) services?*

Participant #7

- Only when we trust the worker or person. Then we will tell them our real concerns. When I feel safe, I can tell the person my problems.

Participant #10

- My job is to provide services. One of the problems I faced was that parents were too depressed to ask for help. One of the parents is suicidal. She was not ready to seek help for herself. Until the parent is able to take care of herself, she won't be able to help her son. Not many parents are like that. However, this is my challenge to get the mother ready to seek for help. Because she trusted me, she came to me and told me about her problem.
7. *Do you think community leaders have a role in helping families who need early intervention/birth to three supports for their children? If yes, what is your role and what information do you need on early intervention (birth to three) support services in order to help?*

Participant #4

- In Latino communities, the word spreads out quickly. They will tell you who to go to and ask for help. They will also tell us what works what doesn't work.

#### Participant #5

- In my Samoan community, relatives, aunts, uncles, and other family leaders are the ones who decide who and where we should get help.

#### Participant #6

- I work in a neighborhood that has a lot of apartment complexes. There is always someone who seems to know something. Often, you find these people at parks, laundry mats, wherever people gather.

#### Participant #11

- In my experience with Native American communities, there was always a person who everyone went to. "Rita" was the one who community members went to for help.

#### Eastside FACES

The following is a summary, themes and session notes from focus group with the Eastside FACES held on January 10, 2006. There were six participants who represented a variety of organizations involved in children and family services including, the City of Bellevue, Children's Home Society, Kinderling Child Development Center, Encompass, Harborview Children's Response Center and Parenting Matters.

The participants were asked eight questions about their experiences with the early intervention (birth to three) services system, barriers for families and their thoughts on how we could increase access and get children into services earlier.

#### Session Summary

Participants believe it is important for families to have a trusted advocate to help them navigate the system and also believe that universal screening would help identify kids and eliminate the stigma associated with a disability. Participants were concerned that schools and physicians, as gatekeepers, are not providing the information and assistance that families need to make informed decisions.

#### Session Themes

Based on the experience of the participants they believe that physicians and educators are not well informed on disabilities or the importance of early screening.

Participants primarily get their information on early intervention from community meetings and events they attend.

Participants believe the biggest barriers for families are: (1) Physicians for a variety of reasons; a wait and see attitude; lack of information on disabilities and services; mixed messages to families; lack of education on the importance of early

intervention and red flags, (2) Parents' denial that there may be a problem, (3) Cultural issues that affect access to services and (4) lack of information on what to do and where to go.

Participants believe the best way to get children into services earlier is to have a trusted advocate helping the family and the availability of free universal screening to identify children early and reduce stigma.

#### Comments Worth Noting

The term early intervention (birth to three) doesn't mean much to the general public and is used in other disciplines without regard to developmental delay.

Child care programs' lack awareness of developmental delay and information on early intervention (birth to three) services.

Parent denial and transportation are barriers to getting needed services early.

#### Session Notes

1. *What has been your experience in working with early intervention (birth-to-three) programs?*

#### Participant #1

- I have done social work and worked as a teacher in a Montessori school. Agencies are scared to tell parents there might be something wrong. When parents are told it is hard for them to find the services they need.

#### Participant #2

- Families tell me they get bounced around and are shuttled from service to service. Even when families get assessed, there are not enough providers. The earlier children get assessed the better.

#### Participant #3

- There is a lack of awareness by the public of what early intervention is and around the warning signs. The word early intervention doesn't mean anything to the public. The word doesn't apply to just early intervention for kids with disabilities.

#### Participant #4

- All parents think their kids are perfect. If a parent is at home with a child they have nothing to compare their child's development with. In rural areas it is easy to know who to call, but in King County it is difficult to navigate. I am worried about doctors having the wait and see attitude. Parents know their child best so if they are concerned they need to be supported to get help. The first three years are so critical.

Participant #5

- I work at Kinderling Center so families come to us. I worry that child care programs lack understanding and awareness of early intervention programs. I think normalizing screenings for all kids would help prevent kids from being stigmatized. Parents are scared but relieved to know their concerns are valid.

Participant #6

- We see difficulty with getting pediatricians to get beyond wait and see. Gatekeepers and child find organizations are not well informed on early intervention and screening. Screening is not well publicized at schools. Schools are not welcoming and screening is not normalized, we could be saying come on in. Physicians and educators are gatekeepers. (All participants agreed)

Participant #4

- There are reasons why screening is not done, agencies are up against budget shortages and if they find the children they need to provide services.
2. *Where do you get your information on early intervention (birth-to-three) services? Do you make this information available to families?*

Participant #1

- We fund organizations to provide services so I find information through reading reports from agencies. We fund programs so I read brochures and attend Eastside FACES meetings. I don't refer parents.

Participant #2

- Our information comes from child care centers, home visits with young moms and early head start.

Participant #3

- I attend two FACES groups that is where I get information and also public health nurses. I also attend community events, especially birth to five events. Beyond that the counselors don't get information on early intervention. There is no flow of information or sharing of information.

Participant #4

- I am a new mom so I read a ton. I get Child Profile which has developmental milestones. I have no idea what the school district does. I assume if I needed information I would call the school district or my pediatrician.

Participant #5

- I am well aware of what's available, I attend meetings, but people I am in contact with have no idea. People are not aware of what agencies like ours are,

not aware of who we are, or think we are a child care agency rather than an early intervention program.

Participant #6

- ITEIP is where we get all of our information. We have a (birth to three) early intervention service so we have a therapist that go into people's homes.

Participant #2

- Child care workers would like to have the information.

3. *What, if anything do you do when you suspect a child has a developmental delay? If you suggested something to a family what was the family's response?*

Participant #1

- I would refer a family to Kindering Center. If a family lived in Seattle I would call the CDMRC at the University of Washington Seattle.
- Parents have two issues, they are skeptical if concerns are raised but also relieved to know the concerns they have had are valid.

Participant #4

- I had a friend who thought there was something going on with her child at an early age but was in denial.

Participant #5

- It really depends on who is saying it how it is received. If child care providers say something on the spot it is not well received, but if done as part of a team it is received better. We use the pediatrician. How it is presented is a big piece.

Participant #6

- We do screening all the time. Parents also report their pediatricians are doing this. We try to gently give them information.

Participant #2

- My experience is very limited. We have so many staff I can go to and they work with families. A grandmother had concerns and the mom was in denial. New moms have nothing to compare their child's development to.

Participant #6

- Moms are isolated. There used to be more opportunities for feedback from family members.

Participant #3

- I would go to my pediatrician or school. My experience with my community is they are high achievers. They expect to have a normal child and there would be denial if their child had a disability. Once they knew they would inform themselves of services.

Participant #6

- My daughters are internet savvy and they would Google for information.

Participant #5

- Families have told me they are savvy, but it is so overwhelming without someone to walk you through or help. Support is really important to a family.

Participant #6

- Finding out if there is something wrong is scary to families.

Participant #5

- Some families were so afraid they pulled their child from program.

Participant #6

- Delays that are not obvious are harder for families to see.

4. *What do you think are the biggest barriers for families trying to access early intervention (birth-to-three) services?*

Participant #6

- Parental denial. (A majority of participants agree)

Participant #2

- Transportation – Having to get from here to there with other children in tow.

Participants #4

- Immigrant families with language barriers. They may lack knowledge of what's available and information may not be translated.
- How people are treated that are from different cultures. My assumption is that programs are pretty embedded in mainstream. I don't see multicultural information.

Participant #2

- What it means to have a child with a disability-the stigma of disability.



Participant #6

- Physicians need courses on disability and early intervention (birth to three) and red flags.

Participants #5

- The wait and see attitude of physicians.

Participants #2

- Physicians are used to fixing people. It has gotten better but still a problem.

Participants #6

- Pediatricians and programs give mixed messages to families.
- I wonder whether insurance plays a part in this. What tests are insurance companies willing to pay for?

Participant #4

- I am aware of what's available because I attend meetings and get information from my physician.

Participant #3

- We need to have information available to all families. It should be a normal process for all parents.

Participant #5

- School districts don't know what exists for three to five.

Participant #1

- When people get the courage up to call someone and don't get a call back or a real person to talk to they get discouraged. Agencies need to have accountability to provide information.

Participant #2

- Families get advice to call their physician and then the doctor doesn't know what's available.

Participant #4

- I had a sister who had a child and at age three who went to speech therapy she had to get over the denial and do what was best for her child. I would love to see this be about the child, it's the loving thing to do. There are things that are not uncommon, like speech therapy. We need to have prevalence information and screenings that are free for all families to normalize the process.

Participant #2

- There needs to be specific information for families on what to look for.

Participant #5

- Money should not be a barrier. No cost for evaluations if you can't afford it.

5. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a disability?*

Participant #4

- I would like to have regular ongoing consultation with an individual from disability organization to help build our toolbox. Also there needs to be a child team that comes together from different disciplines to help families. Better networks and ways of knowing the people so the relationships make it easy for ongoing consultation.

Participant #6

- We have a group within our organization. We do trainings and I give teachers my e-mail and tell them to call me if they have questions. Teachers don't want to appear unaware.

6. *What are your suggestions on how we might reach families and their children earlier and make accessing early intervention (birth to three) services easier for families and their children?*

Participant #1

- Families said there used to be program a long time ago that had an advocate families could call and walk them through. They need someone to help them walk through the systems like a trusted advocate. Funding ran out.

Participant #4

- Families need some type of resource guide, like financial planners give to people. How do you know which program is the best for your child. When I was a child the school did a hearing, vision, screening, etc.. Why can't schools do a developmental screening it doesn't take a lot of time?

Participant #2

- Information should be given with prenatal care like a doula (good friend and support person) that is with you to make sure you get everything you need to know to care for a new baby, with information on where to go and when if you have questions. This becomes a normal thing to do not abnormal.

Participant #5

- Increasing access to free developmental screening.

Participant #2

- Screening at churches. People go there.

Participant #5

- Screening doesn't take long – twenty minutes.

Participant #6

- Screening could be fun. Perhaps obstetricians and gynecologists could be providing information.

Participant #2

- Providing information at the hospital is not a good time, too many other things going on.

Participant #3

- Reframing the issue – We need to find more positive ways to normalizing screening rather than just red flags. All development begins at birth and parents want to learn about it. There is a fear of knowing. Spin it so parents are getting interesting information, like how the brain develops, rather than wait and have the information be fear based.

Participant #4

- I don't recall receiving a lot of developmental information when I had my child. I do a parent newsletter. I would love to know that school districts did screening from birth to five. Screening needs to be done universally like immunizations are.

Participant #5

- Free developmental screenings for all children. It needs to be normalized for all children not wait until there is an issue.

Participant #6

- We need a two prong approach – screening available to parents and education of physicians to do the screenings. Physicians need to be ready.

7. *Any other thoughts?*

Participant #6

- We need more awareness about organizations that provide early intervention and what early intervention is.

## Family Resource Center - Friends of Youth

The following is a summary, themes and session notes from a focus group with participants serving families and children held on January 25, 2006. There were seven participants that represented Northshore Youth and Family Services, Youth Eastside Services, Center for Human Services and Children's Home Society of Washington.

The participants were asked eight questions about their experience with the early intervention services (birth to three) system and their thoughts about barriers to families, how to improve access and get children into services earlier.

### Session Summary

The participants involved in this session are well connected to the early intervention (birth to three) services in their community. They provide screening of all eligible children twice a year and educate their families on milestones and local services. They identified transportation and parent motivation as barriers. They also suggested that training of child care providers on how to screen for a delay, providing therapies in the home, universal screening and better education of physicians would improve the system.

### Session Themes

Participants are well informed regarding developmental delays and local early intervention (birth to three) services.

Participants do screenings every six months and work with families on finding appropriate services if a delay is identified.

The universal and frequent screenings done by participants prepares families through milestones rather than red flags.

Participants identified transportation and young parent motivation as the biggest barriers to getting services.

Participants suggested training of child care providers on how to screen for a developmental delay, offering therapies in the home, offering universal screening and support to families and better education for doctors in medical school would all improve the early intervention (birth to three) service system.

Participants work closely with WIC and public health nurses.

### Session Notes

1. *What has been your experience in working with early intervention (birth to three) programs?*

Participant #2

- We do referrals to early intervention programs and we teach classes for parents on how to advocate and support their children. When we see red flags, we do referrals, for example if a child had delays in language development.

Participant #4

- We use screening tools (Ages and Stages questionnaires) with the parents so that if child scores low we can talk with parents. We do this twice a year with all children.

Participant #2

- We get our kids from doctors, schools (teen moms), and community members. Parents must be under twenty three and baby must be six months or younger to enroll.

Participant #4

- We give parents the information for referral and assist them in getting appointments. If the delay is minor we might provide the intervention ourselves.

2. *Where do you get your information on early intervention (birth to three) services?*

Participant #6

- Kindering Center does training with us several times a year – including speech therapists, physical therapist, etc. We tend to use Kindering Center because they are on the eastside.

Participant #7

- I don't always have the best or most complete list of resources when I need it. Sometimes we have to "do the homework" – internet searches, go to ITEIP listings for resources by counties, etc.

Participant #2

- We have had a number of children go through Children's Hospital for evaluations. This hasn't been an issue financially because it is for assessment/evaluation, not treatment.

3. *What do you do when you suspect a child has a developmental delay? What is family's reaction to referral?*

(Note: these agencies do frequent screenings and make referrals to early intervention programs so we focused on the family reactions)

Participant #2

- It depends on how it is presented. Parents are more accepting if you stress that it could bring the child “up to speed” before school would start.

Participant #4

- Usually, parents are not surprised, they have some sense that something is going on.

Participant #5

- It helps that screening is done regularly and in six month intervals. It helps to have an opportunity to talk about it over time. We try to explain how simple interventions might be helpful rather than quickly identifying a “red flag”.

Participant #7

- Being able to talk about it ahead of time helps and what we will be looking for next.

4. *Is there a delay between when you notice something and when you refer?*

Participant #4

- Usually under four weeks would be typical; some families take longer.

Participant #6

- Referrals to Children’s Hospital can take months.

5. *What are the biggest barriers for families trying to accessing early intervention (birth to three) services?*

Participant#4

- Kindering Center is doing a great job of overcoming the major barriers of language and transportation (probably the two biggest barriers).

Participant#5

- We have a community agency where people might just walk in. We try to touch base with the WIC resource/nurses. Some WIC nurses will stay beyond the standard 4 visits which can be very helpful. Parents-As-Teachers curriculum is taught by us but we have shared with WIC nurses.

Participant#4

- Some states have PAT visits available to any family with a newborn – not Washington.

Participant #5

- The Gates Foundation may be ramping up to fund nursing and early intervention visits.

Participants #3 and #7

- Transportation is a major issue. Also, you are working with young moms who may not have the skills or opportunity to follow through. Fear of taking that step because of their own personal fear or fear within the family.

Participant #4

- Fear or self-blame about the delay can be a barrier.
- One mom is resistant to including the father; father is not accepting. Mom is going ahead without support or the knowledge of father. Another mom was getting conflicting information and needed coaching in being assertive.

Participant#3

- Currently, working with DSHS is a barrier and working with other agencies can be barrier (lack of respect, confusing systems, parents not willing to challenge authority).
6. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a developmental delay?*

Participant#4

- Knowing more about social security benefits; what benefits are available and how to access them.

Participant#3

- Support groups in other languages.
7. *What are your suggestions on how we might reach families and their children earlier and make accessing early intervention (birth to three) services easier for families?*

Participant#6

- Universal access to PAT programs, universal parent support and education for all parents.

Participant#6

- Better education for doctors in medical school and ongoing continuing education.

Participant#7

- Being able to offer therapies in home.

Participant#2

- Assure that child care providers are trained to screen or at least know where and how to refer.

Participant#4

- Utilize community centers as training/support centers. Parents are more comfortable accessing information in their own settings. Emphasize the value of all families receiving the information.

Participant#7

- We can initiate visits with moms, this is huge advantage, we can check and keep checking.

Participant#4

- Continue putting the information on developmental milestones at places (and in languages) that families are likely to access.

Participant#3

- Making sure that single parenting fathers are getting the information they need.



## **Medical Providers**

### Public Health Nurses

#### Session Description

The session participants were six public health nurses attending a monthly meeting at Columbia Health Center in Seattle.

The participants were asked nine questions about their experiences with working with children and families, the barriers families experience, how to increase awareness about early intervention (birth to three) services and supports, and how to reach children and families as early as possible.

#### Session Summary

The participants described working well with the early intervention (birth to three) services and that there needed to be more awareness among parents and practitioners and more information for them to use to help children get into services. They said that practitioners who are hesitant to refer children to services and parents that lack information about services and how important they are can be a barrier to children and families getting connected to services. They recommended additional information to practitioners and parents and recognized that conveying that information may take more “face-to-face” communication than relying solely on printed material.

#### Session Themes

The participants report that awareness among medical practitioners varies and that additional information about early intervention (birth to three) services is needed. Likewise, they report that they receive information about services from a variety of sources, such as early intervention (birth to three) providers, CHAP, newsletters, printed and electronic resources, and advocacy organizations, such as the ARC of King County.

The participants had differing views about how best to convey information about services to practitioners and families. They agreed they needed more information about how the system works, how services are paid for, and how important early services are to a child’s development. They stressed using person-to-person contacts (parents, practitioners, and early intervention (birth to three) providers),

establishing allied provider relationships, and distributing resource material that is useful to practitioners and accessible to parents.

The participants agreed that pediatricians, primary care physicians, and nurse practitioners not referring children is a barrier to getting them into services. They acknowledge that practitioners have limited time during a typical office visit and are sometimes presented with children whose developmental issues or diagnoses are in a “grey area” and are reluctant to alarm parents prematurely. They also cite transportation issues, the stigma associated with disabilities, and access to interpreters and materials that are translated into their native language as barriers for families and children.

All of the participants reported good experiences working with early intervention (birth to three) services, especially as it relates to working as a “team”. They said that having information about how to have a conversation with parents about their children (“what words could I use?”) would be helpful. They said there needs to be information presented to parents that is not “scary”. They also suggested having additional assessment tools that identify “red flags” that parents and practitioners could use would help with the conversation and get children and their families connected with services.

#### Participant Responses

1. *How aware of early intervention (birth to three) services are pediatricians, public health nurses and other practitioners? Do you feel there is a need to increase their awareness?*

#### Participant #3

- It varies widely. Practitioners need more awareness of developmental issues.

#### Participant #5

- There is more awareness and support in hospitals. Once people leave the hospital, there is not as much focus on developmental issues.

#### Participant #1

- If the child’s issues are subtle, the office time available to physicians might not allow further investigation.

#### Participant #4

- Physicians might not want to alarm parents if what they are observing is subtle. They might delay further assessments.

#### Participant #3

- Pediatricians are sometimes upset if referral is coming from “outside”. They may feel the need to document the diagnosis “absolutely”. They may want to be “in the loop”. They don’t want to be blindsided by a referral.

Participant #5

- Physicians may feel that they are referring to a specialist rather than just getting an assessment. They may feel the need to justify and document the referral.
- Developmental delays are in a “grey area” and this may be an issue. Developmental issues are not like other diagnoses that are more easily defined.

Participant #1

- Some pediatricians are hesitant to “feed into unfounded fears of parents”.

Participant #2

- Physicians may be concerned about the label. Parents are already resistant.

Participant #1

- It is possible that physicians might think that early intervention (birth to three) services come out of capitated payments and that they might be trying to conserve their funding.

2. *Where do you get your information on early intervention (birth to three) services?*

Participant #6

- I get information from CHAP and Kid Care.

Participant #5

- I go to the local agency that provides early intervention services.

Participant #6

- I call service providers directly.
- I review newsletters and check printed and electronic information sites.

Participant #4

- I use the “Where to Turn Book” from the King County Crisis Clinic

Participant #1

- The ARC of King County web site.

3. *What ways do you feel would be effective in communicating with pediatricians and pediatric clinics? (written material, brochures, etc.)*

Participant #6

- Printed brochures would be helpful.

Participant #2

- Printed brochures don't work as well with families. They need a phone number that would connect them with a specific person or service.

Participant #3

- Physicians need Continuing Medical Education credits and like to learn through case studies.
- Parents need things that they can do for their children and ways they can be involved.

Participant #1

- When you are involved in services, it's difficult to keep current with resources.

Participant #2

- Physicians' limited time may not allow for subtle or less medically critical issues.

Participant #1

- Physicians may not understand that assessments are free to people and provide detailed developmental information.

Participant #6

- The Referral Coordinator position could be key but they may not be aware of the resources.

Participant #2

- Follow-up after the referral is important. It may not be happening.

4. *What are the critical things pediatricians and clinics need to know about early intervention (birth to three) services?*

Participant #4

- Physicians need to know who is eligible for early intervention (birth to three) services.
- Other participants say everyone is eligible.

Participant #1

- Services are free, paid for through early intervention (birth to three) funding.

- The earlier the intervention, the better the outcomes.
- There is a barrier from physicians who are not willing to recommend or offer the referral. Medical culture is at the “hub”, but some physicians may not know enough about early intervention (birth to three) services.
- Early intervention (birth to three) services are so important, there is so much offered. They are the “Cadillac of service”.
- There are services that are not available at any other time, such as transportation, parent-to-parent groups and family resource coordinators.

Participant #3

- We should err on the side of providing services rather than withholding services.

Participant #5

- Physicians are hesitant to be involved in “maybe” diagnosis when they are uncertain.

5. *At what age or under what conditions would you refer a child for early intervention (birth to three) services?*

Participant #3

- Premature babies, although it would not be automatic.
- Babies not meeting developmental milestones when considered as a whole, rather than a specific measure.

Participant #1 (and others in agreement)

- I consider the child’s environment, but I would still refer based on some “red flags” such as feeding difficulties or delays in gross motor and language development.

Participant #6

- There is increased awareness of autism, parents and practitioners are more aware of autism.
- If a child has a history of birth trauma or conditions present at birth.

Participant #3

- A child of parents with developmental disabilities.

6. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services?*

All participants

- Pediatricians, primary care physicians and nurse practitioners are not referring children.
- Transportation for families is a barrier.
- There are language and cultural barriers; stigma, reliance on the availability of interpreters, and paperwork that is only in English.
- Parents don't know how to find services and supports.

7. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a disability?*

Participant #1

- Knowing what wording to use. What are the words that families will key into?
- The words "development" and "early intervention" don't work.

Participant #2

- What terminology would be effective?

Participant #6

- The current ITEIP booklet could be "scary" for parents, especially when their child is in a "grey area" – delayed but not yet diagnosed.

8. *What has been your experience in working with early intervention (birth to three) programs?*

All participants

- Great!
- We work collaborative as part of the same "team".
- We share information.
- They give us feedback on children and families that are not yet in services. They are willing to share their expertise.

9. *Since “waiting and seeing” regarding early development may mean a loss of opportunity for intervention when the brain is developing most rapidly, how can we encourage pediatricians to suggest a screening or complete evaluation earlier rather than later?*

Participant #1

- A medical home team can be instrumental.

Participant #3

- They [physicians] want the call from public health nurses to document the referral and collaborate with them.

Participant #5

- Physicians should have a standardized, “best practices” approach to direct children to intervention services without the need for a label or diagnosis.

Participant #1

- There is the “red flag tool” from Kids Get Care, but it may not be used, although training has been available.

Participant #2

- A simple chart (e.g. with bullets) that establishes best practice might be useful.

Participant #1

- Many physicians do not use the developmental screens that are available, such as the Denver [Developmental Scale]. Those measures are time consuming.
- There is a “red flag tool” available.
- Just sending information and tools to physicians is not effective,
- Insurance and health plans influence physicians’ plan of care.
- Children with Special Health Care Needs “red flag tool” should be incorporated.

## Physician Interviews

The following is a summary, themes and session notes from telephone interviews with three physicians conducted in October and November 2005.

The participants were asked ten questions about their experiences working with children with disabilities and early intervention (birth to three) services, the barriers families’ experience, and their thoughts about how to improve awareness and access to services.

## Session Summary

The participants agreed that that physicians and parents need to be better educated about the importance of early screening and where to get help with information and referral. They all agreed that developing working relationships and communicating with families and service providers would help make the system more manageable for practitioners and families.

## Session Themes

The participants presented a mixed assessment on the awareness of early intervention (birth to three) services among physicians. One physician thought peers were generally aware of early intervention (birth to three) resources another did not. A third thought that it varies. Pediatricians are thought to be generally more aware, but see fewer children.

They mentioned referring families to birth to three centers. They cited a number of sources of information including early intervention (birth to three) centers, the Children's Hospital Neurodevelopment Center, the Children with Special Needs program, Family Resource Coordinators and ITEIP.

The participants generally agreed that communicating with practitioners and families has been done face-to-face with people they have relationships with. For practitioners, that could include early intervention specialists and therapists that they know and trust. For families, this could include parent groups and brief written material.

They said that it is critical that practitioners and parents know the value of early screening and although some diagnoses are difficult to make, especially with a very young infant, it's worth it.

The participants cited several conditions that would lead them to refer a family to services. They generally agreed that missing developmental milestones and parental concerns would be important indicators.

The participants gave several examples of barriers that interfere with a family receiving services. Most often, they cite a system that is difficult to manage, services that are not well coordinated, and the time and transportation resources it takes for parents to get to treatment sessions. The issue of the lack of insurance, parental knowledge, and a physician "wait and see" attitude were also mentioned.

The participants described their experiences with the early intervention (birth to three) system as being generally good, although one participant spoke of it being a "one-way street" for information and recommended that physicians receive some feedback after referring a family to services.

There was a consensus among providers that providing more information to physicians and educating parents was important to getting children into services earlier. They spoke of how both are "willing to wait". One participant felt that offering services to families that are less threatening, like preschool or early therapies' are easier to promote.



It should be noted that early childhood development is a significant element of each of these physician's work and they are likely more involved with early intervention (birth to three) services than other physicians.

## Session Notes

### Physician Interview #1

#### Session Description

This was a forty-five minute phone interview with a physician in South King County on October 20, 2005.

The participant was asked ten questions about access to early intervention (birth to three) information, barriers experienced by families, how to increase awareness about early intervention (birth to three) services and supports, and how to reach children as early as possible.

#### Participant Responses

1. *How aware of early intervention (birth to three) services do you think medical practitioners are currently? Do you feel there is a need to increase their awareness?*
  - Physicians are not aware of early intervention (birth to three) services. I've been a Pediatrician in a family practice for thirteen years and I'm still reminding people about Child Find. This is especially true because kids see a lot of family practitioners.
  - Pediatricians are more informed but see fewer kids.
  - Practitioners are interested but uninformed.
  
2. *Do you know where to refer a family for follow-up or obtaining early intervention (birth to three) supports?*
  - I have two options, the Kent Child Therapy Center and the Birth-to-Three Developmental Center. Others practitioners refer to the Birth-to-Three Developmental Center.
  - The Birth to Three Developmental Center is becoming known in the community. Public health nurses use it and people refer themselves.
  
3. *Where do you get your information on early intervention (birth to three) services?*
  - I use the Society of Developmental/Behavioral Pediatrics for clinical information. I also use Children with Special Health Care Needs program in the Health Department.

4. *What ways do you feel would be effective in communicating with medical practitioners and clinics that frequently serve children? (written material, brochures, etc.)*
- When the information comes from someone people know it works the best. Having someone come to an all staff meeting with a brochure and a presentation to help get people on board.
5. *What are the critical things pediatricians, family practice physicians, nurses and other clinic staff need to know about early intervention (birth to three) services?*
- You have to screen because in early infancy it is difficult to tell without a test.
  - Parents aren't ready for a conversation about disabilities and providers aren't there yet either.
  - It's worth intervening early.
  - There are resources.
  - I wish I could say there is one web site or one place to go, but I can't. Parents could link up and print the material. I have seen the web sites but they're not quite there.
  - These things are not obvious or easy to diagnose. You have to have training and an assessment tool, especially when trying to identify autism at an earlier age.
6. *At what age or under what conditions would you refer a child for early intervention (birth to three) services?*
- If I had concerns such as with babies who have gotten out of a high-risk nursery. I would refer all of them.
  - If they had an ASQ screening at four months, I would consider referring for things like communication, motor skills, or asymmetry in tone.
  - If the assessment was not clear, I would check again after two months.
  - I wait until they've had some shots. I try to wait for two months so children that are premature or experienced a traumatic birth don't catch something.
  - Some literature suggests maternal depression could be an indicator suggesting that the child be referred, but it's hard. Screens really help. It helps take the pressure off of the conversation.
7. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services?*

- Families that lack of insurance.
- I see a young Latino family with two sons. One son was born in Mexico the second son born in the United States. The son born in the United States is getting a completely different level of care from what the son born in Mexico received there.
- People are doing what they can do with what they have.
- The service system is not centralized. Physicians can't be care coordinators.
- The coordination is tough especially for kids that see multiple therapists.
- Half of the time I don't get the reports from other practitioners – trying to keep up.
- Transportation is a problem for families. Buses don't go east/west. Families with multiple sessions have difficulty.
- Parents can't take time off.

8. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a disability?*

- I would like to know about therapy and evaluation for sensory integration in my area. How to get evaluations, recommendations, and the "gear that they use".
- I would like to know where to find a therapist.
- Therapy for autism. Haven't tried the new biomedical center. Several parents are aware that the recommendations for a child with autism are for intensive therapy.
- The UW CHDD provides developmental preschool and multi-evaluations for "about one percent" of the kids that need it. There is much more demand like "One hundred times more".

9. *What has been your experience in working with early intervention (birth to three) programs?*

- I've had a good experience with the Kent Child Therapy Center and excellent experiences with the birth to three programs and the Neurodevelopmental Clinic at Children's Hospital.
- I have not been as happy with the Neurodevelopmental Clinic at Mary Bridge but it's getting better.
- Services like physical therapy or nutritional follow up are driven by what they were able to provide rather than what the child needs. It's a financial issue.

- You want to feel good about what you provide so you don't acknowledge not being able to provide it. It's too uncomfortable.
  - Insurance companies want providers to say, "this is enough for you".
10. *Since "waiting and seeing" regarding early development may mean a loss of opportunity for intervention when the brain is developing most rapidly, how can we encourage pediatricians to suggest a screening or complete evaluation earlier rather than later?*
- It is hard to make the case with infants, but I have found that developmental centers and Child Find are easy to offer to families because it comes with preschool and therapy. It is appealing for providers and parents to connect with preschool to get them in at age three rather than four. Preschool setting at age one is a big draw for families and lessens the stigma associated with therapies.
  - For a child under age one it's a harder sell. Before age one the exercises are easier to offer families.
  - Part of "wait and see" is the uncertainty. So you'd want an intervention with little "down-side" or an easy sell.
  - As a parent and developmental pediatrician, I was shocked having a physical therapist identify things in my child that I didn't see. Others like behavioral specialists or infant developmental specialists can see things that practitioners and parents can't see.
  - We're getting smarter at things. We can now assess boys based on their receptive language abilities rather than productive language, which allows us to assess language earlier.
  - A possible solution could be encourage practitioners to hand off the conversation with parents to a specialist, or a family resource coordinator, rather than try to meet the family's information needs during the brief office visit.

## Physician Interview #2

### Session Description

This was a forty-five minute phone interview with a physician in Seattle on October 20, 2005.

The participant was asked ten questions about experiences with working with children and families, barriers for families and how to increase awareness about early intervention (birth to three) services and supports, and how to reach children as early as possible.

## Participant Responses

1. *How aware of early intervention (birth to three) services do you think medical practitioners are currently? Do you feel there is a need to increase their awareness?*

- I'm a pediatrician. Among pediatricians, most of us are aware that there are services available in the King County area. Most of us are aware of birth to three and neurodevelopmental centers that are available in the area.
- A lot of my colleagues won't refer to a birth to three center when there is a minor delay. In that case, they would probably refer the child to a specialist. They look at birth to three as a place for someone with multiple delays.

2. *Do you know where to refer a family for follow-up or obtaining early intervention (birth to three) supports?*

- I would use the birth to three center in their area.
- When I was a resident in the area, they trained us to use the central number to call CHAP that you can refer people to. And they refer people out, maybe some people know about that.

3. *Where do you get your information on early intervention (birth to three) services?*

- I use the birth-to-three center in my area or the neurodevelopment center at Children's Hospital. My colleagues use them as well.

4. *What ways do you feel would be effective in communicating with medical practitioners and clinics that frequently serve children? (written material, brochures, etc.)*

- For families I would develop a one-page fact sheet that tells people what is available if they are concerned about their child. It could be distributed to child care providers and passed on to families. It could reach a lot of people at Babies Are Us, or cross marketing with baby stores.
- PEP groups and Great Starts programs and hospital-based healthy baby classes and birthing centers are good places to reach people. You could tie it into their mailing.

5. *What are the critical things pediatricians, family practice physicians, nurses and other clinic staff need to know about early intervention (birth to three) services?*

- Information via email or fax such as the one-page from the Department of Health, One page, that can be easily read, introducing services and reminding us that services are available.

- You should consider a direct mailing to AEP or the (WSMA) Washington State Medical Association.
6. *At what age or under what conditions would you refer a child for early intervention (birth to three) services?*
- Most pediatricians do a developmental assessment at the well child visit such as a Denver Assessment or a general gestalt.
  - If there is a delay, I would broach the subject with the family to seek further help. I would refer to either a birth to three center, a speech or physical therapist or a neurodevelopment clinic or make a decision to follow to see how things progress.
  - I would consider parents concerns, combination of both assessment and parent input.
  - If it's something obvious and the kid won't grow out of it such as a severe language delay or autism I would definitely refer.
7. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services?*
- Parents just don't know about developmental issues or they have enough denial to keep them from finding out.
  - Some providers don't listen to parents.
  - Families find that getting through the system is too complicated and takes too much time. It takes too long to get an appointment and they lose momentum.
  - It's hard for some parents to go to a program. Finding the time in the day to go to the centers is difficult for some families.
8. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a disability?*
- I wish there was a clearinghouse of information, one phone number or one web site that people could go to. A clearinghouse for parents who are worried could help them get social support, information on resources, birth to three programs, parent support groups, and help with preschool.
  - Family resource coordinators are essential. A person that families could talk too would be key. It's nicer to have them talk to somebody who could help.

9. *What has been your experience in working with early intervention (birth to three) programs?*
- It's a "one way street". I refer to birth to three centers but I rarely hear back from them. I do hear about it from parents the next time I see them. Some programs are better than others.
  - When you make a referral you should get a letter back. It's a basic standard of care. It would be great to have the feedback.
10. *Since "waiting and seeing" regarding early development may mean a loss of opportunity for intervention when the brain is developing most rapidly, how can we encourage pediatricians to suggest a screening or complete evaluation earlier rather than later?*
- Education. Most parents don't know that early intervention (birth to three) services exist. There is a huge market of parents that don't know it's out there. Most families won't need it. Others know of a day care center but not a early intervention (birth to three) program.
  - Parents don't want to hear bad news. Physicians and parents are willing to delay referring families to services. To overcome this, we need to educate parents about the utility of early intervention (birth to three).

### Physician Interview #3

#### Session Description

This was a forty-minute phone interview with a physician in Seattle on November 11, 2005.

The participant was asked ten questions about access to early intervention (birth to three) services, barriers experienced by families, how to increase awareness about early intervention (birth to three) services and supports, and how to reach children as early as possible.

#### Participant Responses

1. *How aware of early intervention (birth to three) services do you think medical practitioners are currently? Do you feel there is a need to increase their awareness?*
- It varies. Maybe a quarter of the practitioners are fairly aware and fifteen percent are very aware. There are maybe an equal number that are not very aware and about half that are somewhat aware of available services.

2. *Where do you get your information on early intervention (birth to three) services?*
  - The ITEIP web site, the Family Resource Coordinators, Children's Hospital, the Children with Special Needs program and the Medical Home Leadership web site ([www.medicalhome.org](http://www.medicalhome.org)).
  
3. *What ways do you feel would be effective in communicating with medical practitioners and clinics that frequently serve children? (written material, brochures, etc.)*
  - Face-to-face is important.
  - Care coordination in the office with a special health needs nurse would be really helpful.
  - A person can leave brochures, but it's the face-to-face relationship that is important.
  - Parent/family advisory groups in primary care practices can be helpful (references a model in Skagit Valley) Collaborative spirit. Advisory groups can put up information and bulletin boards. Practitioners don't have time to do that. Team work.
  - Medical home web site, UW center on human development and disabilities/DOH children with special health care needs.
  
4. *What are the critical things pediatricians, family practice physicians, nurses and other clinic staff need to know about early intervention (birth to three) services?*
  - With one phone call early intervention (birth to three) services will step in and communicate back to you about what's going on with that child.
  - Early intervention works well for some things and much is being done to study its effectiveness.
  
5. *At what age or under what conditions would you refer a child for early intervention (birth to three) services?*
  - Any age depending on circumstances. If a child is missing developmental milestone or if a child has a known disorder, such as Down's syndrome. Listening to a parent's concern is important.
  
6. *What do you think are the biggest barriers for families trying to access early intervention (birth to three) services?*
  - Physician reassurance. The "wait and see".



- Lack of communication between families and the system.
7. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a disability?*
- Networking. Meeting with Family Resource Coordinators. They are the “go to” persons.
8. *What has been your experience in working with early intervention (birth to three) programs?*
- Generally good.
  - The system needs more personnel and more services. I’d love to get rid of barriers at age three and expand services to age five.
  - All the early childhood is formative. We need to get the studies to convince the “naysayers”.
9. *Since “waiting and seeing” regarding early development may mean a loss of opportunity for intervention when the brain is developing most rapidly, how can we encourage pediatricians to suggest a screening or complete evaluation earlier rather than later?*
- We need to get the tools in the hands of parents and other providers, such as day care centers.
  - The Center for Children with Special Needs (Children’s Hospital/DOH). They put out a new sheet that helps parents along. It encourages parents to look closer at developmental issues.

## WIC Nurse Interview

The following is a summary, themes and session notes from a phone interview with a WIC nurse on January 27, 2006. The session lasted about forty-five minutes.

The participant was asked seven questions about how families get referred for services, barriers for families and ways to improve access.

## Session Summary

This participant, a WIC nurse, reported having good access to information about child development and early intervention (birth to three) services and public health nurses for assessments. This person acknowledged barriers in transportation and child care.

## Session Themes

This participant reported having access to a variety of resources for information and referral for child development and early intervention (birth to three) services.

This participant valued and relied upon the relationship with, and access to, public health nurses to make sure children are assessed. The person also spoke about how much families trust them.

Transportation and access to affordable childcare is a barrier for many families.

This participant suggested that all families have access to information about child development. This information should go to a broad audience.

## Session Notes

1. *What has been your experience in working with early intervention (birth to three) programs?*
  - I've had more experience in another state as a graduate student doing home visits for infant and toddler programs. When I came to Washington thirteen years ago, I knew of some children that were participating in child development centers. We have children that come through Childhaven that are in crisis – and an assessment is done. Public health nurses are the assessors and they refer families on to services after initial screenings.
  - We refer families to public health nurses and bring them in on the team because they do the assessments. They do many things with the families. They do consults for children with special needs.
  - We refer both within our district and outside the district if we have a family that works and receives services here but lives in another area.
  
2. *Where do you get your information on early intervention (birth-to-three) services?*
  - Experience. We're not big on brochures because we see them in the parking lot. We give people directions and phone numbers for food banks, information about immunizations, lists of physicians, and information about how to get a medical coupon and food stamps.
  - It's interesting how much people trust us. If we don't know something we will we'll try to find it out for them.
  - Sometimes people get intimidated by printed information.
  - Two-sided information sheet, "Family Resource Directory" King County [www.ci.seattle.wa.us/crisisclinic](http://www.ci.seattle.wa.us/crisisclinic). This lists a variety of individual and family supports and services. Including disability services and parent support such as the ARC of King County and Kids Care.

- “Where to turn” directories. King County Health and Human Services the Crisis Clinic, the University of Washington.
3. *What do you do when you suspect a child has a developmental delay?*
- I refer the family to the public health nurses.
  - We also have physicians and nurse practitioners if we have concerns. They seem responsive.
  - It’s amazing how many parents bring up concerns.
  - People seem to trust us here and we encourage them and they look to us for information. So often they’re responsive. I might say, “You might find this useful, here’s somebody that can tell you more about it.”
  - Fifty percent of babies in Washington are receiving WIC services.
4. *What do you think are the biggest barriers for families trying to access early intervention (birth-to-three) services?*
- I suspect that transportation is a big barrier depending upon where the family lives in relation to the development centers. Families do amazing things to get their kids into their treatment sessions.
  - Getting child care for other children in the family is difficult and expensive.
  - Just the session scheduling can get intense. We see children with many disabilities and they have to go to a number of other programs and treatment sessions.
  - There are good programs that come into the homes and families appreciate it.
5. *What is the one thing you wish you had more information about that would help you in working with a family that has a child with a disability?*
- I go to the Internet. I go to providers. I usually can find what I need for families. I also go to advanced practice nurses in the King County Parent Child Health Division.
6. *What are your suggestions on how we might reach families and their children earlier and make accessing early intervention (birth to three) services easier for families and their children?*
- Child Profile. Families are sent information about child development. They try not to scare families, but it might be an appropriate way to get developmental

information to families. They go to a broad audience, not just low-income families.

- Working families that are self-insured or do not have Medicaid may have limited access to therapies. Until you get a major diagnosis many families cannot get medical coupons.
- Another program that is under-funded is Head Start. It starts at age four. There is a good opportunity to get a child an assessment from the Head Start program.

## **Early Intervention Providers**

The following is a summary, themes and session notes from phone interviews with early intervention (birth to three) providers held from December 22, 2005 through January 30, 2006. There were three participants.

The participants were asked eight questions about how families get referred for services, barriers and ways to improve access.

### **Session Summary**

From the provider's perspective, parents, their physicians, and other people in their lives can be a great asset or a significant barrier to children getting the early intervention (birth to three) services they need when they need it. Likewise, they viewed raising the awareness among parents, practitioners and others involved with children about early intervention services and the value of them to the child who needs them as essential to getting children and their families connected with services.

### **Session Themes**

The participants describe a variety of ways that families and their children come to the centers, most frequently through a referral by someone in the medical community such as physicians, public health nurses, and community clinics. Likewise, they report that the referral agents have a varying amount of information about early intervention (birth to three) services, how they are funded, etc. They all report that the practitioners that frequently refer families and have a relationship with the center have the highest level of knowledge about early intervention.

A family's knowledge of typical child development or their observations of typically developing children that raise their concerns about their own child's development were thought to help families get connected with services. Participants also mentioned physicians that are aware of early intervention (birth to three) services and are more likely to refer are others in a family's life, such as other family members, friends, and community organizations such as Head Start programs.

Families that were not aware of typical child development or had concerns but were not emotionally ready to discuss their child's development and possible interventions made getting children into services more difficult. Participants also discussed a "wait and see" attitude on the part of the physicians and other family members and friends as also delaying children getting into services.

All of the providers stressed the importance of physicians and their knowledge of the early intervention (birth to three) system and their relationships with providers and others involved in child development in any effort to increase awareness and access to early intervention services. They also thought that working with parents in particular and the community in general about child development and early intervention (birth to three) services would help reduce the fear and stigma associated with childhood disabilities.

The participants recommended increasing awareness of childhood development and early intervention (birth to three) services and broader developmental assessments at locations where children are, such as child care centers and Head Start programs, that would help identify children who could benefit from services earlier and help focus the conversation between parents and their physician, nurse, or other person involved with their child.

## Session Notes

### Provider Interview #1

1. *What are the sources of referral for children and their families to early intervention (birth to three) services?*
  - The majority of our referrals are from pediatricians and public health nurses. Ninety percent of referrals are from physicians.
  - We also get referrals from other social services agencies and programs such as CHAP. We get referrals from other early intervention service providers if a family is closer to our center. Not many families' refer themselves.
2. *How familiar do you think referral sources are with early intervention (birth to three) resources?*
  - Physicians we work with are familiar enough with us. I don't know how many other physicians are out there that are not familiar. Physicians are pretty well known to us. After twenty-five years, referral sources get to know you.
3. *What are three things that you think help families get connected to early intervention services?*
  - Family knowledge of typical child development so they can bring questions to the attention of their physician. Without information, families take a "wait and see" attitude.
  - Routine check-ups would lead to physicians making referrals.
  - Knowledgeable pediatricians would help families get connected.
  - Other community resources. What's their knowledge base? Informal gatherings, child care providers, churches, friends and family.

- I wonder about child care providers. Therapists go to centers to see one child and observe a couple of other children that are not part of our caseload that possibly should be. Providers may see it as a threat.
- We don't get any referrals from child care providers.

4. *What are the biggest barriers to children getting served early?*

- Parental knowledge
- I don't know how many physicians take a wait and see attitude.
- Finances are a barrier to some degree, although early interventions should be available to all children ages birth to three. It's misleading about what is fundable and what is not. Some physicians and hospitals think that everything is free, and that is not how the system works. People are led to believe that therapy is free.
- Stigma. Some families are in denial. The physician may see it, but some families in denial don't want to get services from a treatment center. Mothers sometime report that they are ready for services but that the father is in denial.

5. *To what extent do those barriers delay children getting into services?*

- For our first 20 years we grew to a point. In the next four years we doubled and in the next two years we doubled again. We're experiencing twenty-five percent per year growth. In light of that I would said there are no major barriers or we would not be growing as fast as we are.
- We get referrals for two week olds, compared to two year olds, twenty-five years ago. There are still kids falling through the cracks, but it seems like the word is out there. I've heard local and state averages are comparable to national averages of two – two and a half percent.
- We will have capacity issues if we get more kids at a younger age, which means they are in the system longer. There are capacity issues already. Kids just can't get in some centers. We are struggling to find therapists.

6. *What would be the one thing that you would change in the referral process to help children and their families get connected to services early?*

- I think it starts with the physicians.
- I also think that child care is important. I don't think there is enough done there. I've heard enough times from therapists who see kids in these settings that are not on our caseload but should be.

7. *If you were in charge of a public awareness campaign to get kids into services earlier, who would be your primary audiences?*

- Physicians
- I would push to get general awareness about CHAP.
- School districts are required to participate in Child Find, but I don't think they are doing a very good job. The schools spend a lot of time and energy and generate few referrals. They don't get money for it. They spend their energy and efforts and training to K-12. They're required to provide services from age three to five. The resources are watered down. Identifying babies is not on their priority list.

8. *Do you have any other thoughts you'd like to share?*

- There are great physicians out there referring. I don't know how many are not referring but focusing on those that do not refer might have the biggest return.
- I think you'll get more bang for your buck educating child care providers because of the numbers of kids they see.

#### Provider Interview #2

1. *What are the sources of referral for children and their families to early intervention (birth to three) services?*

- Virtually all of our referrals come from the medical community, physicians, public health nurses, Children's Hospital, University of Washington. Parents are usually urged by physicians to talk with us.

2. *How familiar do you think referral sources are with early intervention (birth to three) resources?*

- *I think it varies. I think what happens in some cases is that they are more familiar with those they've worked with and have a working relationship with.*
- After two or three referrals, people become familiar with us. I don't know how familiar they are if somebody needs something that is not as obvious. CHAP has been really good.
- Physicians weren't willing to refer through the Health Department interim family resource coordinators. After that, family resource coordinators were placed in centers.

3. *What are three things that you think help families get connected to early intervention (birth to three) services?*

- The primary care physician is the most important person. It becomes a problem when you have a physician that doesn't refer, but we see very few of those.



- CHAP has been a wonderful resource. It doesn't work with the majority of kids, but works well for kids that would otherwise fall through the cracks. It helps smooth the system. They are the central referral number and are listed in public education material.
- We get some of our referrals from Head Start.

4. *What are the biggest barriers to children getting served early?*

- Parents not ready to have the conversation about their child presents a barrier.
- Medicaid and Medicaid eligibility requirements - insurance in general. Co-pays and deductibles can be a barrier. Families are concerned about insurance and financial issues. That becomes a barrier.
- We work with families with a number of socioeconomic issues, such as homelessness or poverty where they don't have the wherewithal to put it together. We work with them, but it can take a long time for families. It makes it look like kids could've gotten into services earlier.
- Some families are reluctant to get involved with systems in general.

5. *To what extent do those barriers delay children getting into services?*

- I think the socioeconomic barriers are really difficult. Insurance is less a problem, but for those families it's a big deal. A lot of our energy goes into that part of our caseload.

6. *What would be the one thing that you would change in the referral process to help children and their families get connected to services early?*

- The referral system is pretty good. In the last four years at any time about half of the programs are full.
- The one place I would change would be to talk with the centers that get the referrals. We know that physicians who refer long after they should have and try to pin point those physicians. Our outreach is ongoing. Part of our talking with physicians is part of it, but there are some people out there for whatever reason, don't refer. We should have a campaign that focuses on them rather than general physicians.

7. *If you were in charge of a public awareness campaign to get kids into services earlier, who would be your primary audiences?*

- My bias is always toward people that have more problems.
- There should be a strong education program through the public health nurses. You have to update the information.

- Head Start programs.
- We should have an ongoing screening program in day care and Head Start. We've done some of it, but it's never been really successful.

### Provider Interview #3

1. *What are the sources of referral for children and their families to early intervention (birth to three) services?*
  - Word of mouth, school districts, public health nurses, (CHAP) Community Health Access Program.
  - There is no program like ours in the community. People are referred by friends and neighbors.
2. *How familiar do you think referral sources are with early intervention (birth to three) resources?*
  - Probably pretty minimal. They know we help kids that are having difficulty, but they may not know much about how the service is funded and what's available.
3. *What are three things that you think help families get connected to early intervention (birth to three) services?*
  - Another family member.
  - More often, mothers get to the end of their rope. They get scared and finally seek services. Their parental instinct tells them that something is not quite right and they are looking for answers.
  - When parents see other typically developing kids playing, motor, language development, and cognitive play skills. They just start looking for answers.
  - Our center offers programs for a wide age range and mostly typically developing kids. So a lot times parents are bringing their older child for preschool and ask about a younger sibling's development.
  - Publications that we have out can help families get connected, but they seems to have a very small impact, such as flyers in physician offices.
4. *What are the biggest barriers to children getting served early?*
  - Lack of knowledge that there are services out there. Even in our own town, there are many people that don't know we are here.
  - Parent's fear and denial.

- People worry that it will cost them more money than they have.
- The “wait and see” attitude. Sometimes physicians tell them not to worry about it. Sometimes other family members say the same thing.
- Some people don’t want to get government services because of stigma or mistrust.
- Transportation
- Some people resist a home-based service.
- Cultural barriers

5. *To what extent do those barriers delay children getting into services?*

- It’s a big deal because the positive effect of treatment on children’s abilities if they get them. The long term impact on children is very significant.
- It’s a huge stress relief to families when they get connected
- It’s important to get families and children connected with services because early intervention is limited to age three.
- The sooner parents get in and get going the healthier the family will be.

6. *What would be the one thing that you would change in the referral process to help children and their families get connected to services early?*

- Greater acceptance in communities that disabilities are just a different kind of normal.
- Stigma. It doesn’t have to be the tragedy that people often think of it as.
- Having inviting programs where parents can feel relief and that someone cares.
- We embrace family support and do our best to alleviate their concerns - families first, rather than programs first. Some programs are more institutionalized and not as focused on the families.

7. *If you were in charge of a public awareness campaign to get kids into services earlier, who would be your primary audiences?*

- Focus on the child. All children are valuable. Something that sends the message that all children are loved and add something and deserve the best start that we can give them.
- Everybody deserves a good beginning. Each child deserves the best start.

- With every toddler group we use Ages and Stages screening tool that parents use, and parents actually turn them in.

8. *Do you have any other thoughts you'd like to share?*

- As far of the system goes, there is a lack of state leadership in this system.
- There is a better job being done with physicians about early child development. Physicians need to be able to advise parents "yes, we could check this out".
- Connecting with physicians about the importance of early intervention and what to look for.
- We need to normalize the screening process and screen all children.