

# **Young Children with Special Health Care Needs in San Francisco:**

**Report on Focus Groups with Families of Children with Special Health Care Needs,  
and the Professionals Who Work With Them**

## **Who are children with special health care needs?**

HRIIC and First 5 San Francisco had adopted the definition of children with special health care needs used by the federal Maternal and Child Health Bureau (MCH):

*Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

This document summarizes the results of six (6) focus groups with parents of children with special health care needs (ages birth through five), and the professionals who work with them. The findings reported here provide insight into what families and professionals have experienced in seeking and receiving services through the service system.

The High Risk Infant Interagency Council (HRIIC) conducted these focus groups as a companion to a needs assessment that analyzed data on estimated numbers of children with special health care needs (ages birth through five) living in San Francisco, the number of children receiving services from four major public agencies, and the estimated number of children with unknown special health care needs (i.e., children with special health care needs who may not have been eligible for or receiving services from the four participating agencies).

## **Purpose**

These focus groups were designed to seek information on the following areas:

- Identification of children and referral to the appropriate agencies
- The process of assessment
- The coordination of services, both within and between agencies

The individuals participating in the focus groups were not selected in a random manner and their views should not be seen as representative of all parents of children with special health care needs and the professionals who work well with them. However, the similarity in the findings of these six groups suggests that the issues identified are important in our efforts to improve the system for families and their young children with special health care needs.

## **Participants**

- A monolingual Spanish-speaking focus group for families was held at Mission Head Start, and included 7 parents whose children ranged in age from 1 year to 5 years. The special needs of the children represented included autism, Down Syndrome, developmental delays, and vision impairment.
- An English-speaking focus group for families was held at Open Gate, and included 9 parents whose children ranged in age from 1-1/2 years to 4 years. The special needs of the children represented included language delays, vision impairments, hearing impairments, cerebral palsy, cleft lip/palate, developmental delays and fetal alcohol syndrome.
- A Chinese-speaking focus group for families was held at Open Gate, and included 16 parents whose children ranged in age from 9 months to 5 years. The special needs of the children represented included speech and language delays, behavioral concerns, and autism.
- HRIIC members participated in focus groups at a regular HRIIC meeting, and included 13 professionals, including representatives from early intervention programs, Golden Gate Regional Center, California Children Services, San Francisco Unified School District, Dept. of Public Health, Early Head Start, Children's Council, San Francisco General Hospital, and one parent.
- Staff from California Children Services Medical Therapy Program participated in a focus group, and included occupational and physical therapists, one social worker, and one physician.
- Professionals attended a focus group held at Support for Families, and included 11 professionals, including representatives from Head Start, San Francisco General, child care mental health consultation projects, Kaiser Permanente, San Francisco Community Mental Health Services, Department of Public Health and a teen parenting program.

Groups were facilitated by the following individuals: the coordinator of HRIIC, an Open Gate staff member (Spanish-speaking group), a parent representative of HRIIC (English-speaking family group), and a Chinatown Child Development Center staff member (Chinese-speaking group).

## Outreach and Identification

(How do families first find out about possible services and supports for their child, and how are they referred to agencies?)

### What works well?

**When children are in the hospital and have a condition that is obvious at birth, referrals to agencies seem to happen quickly.**

*“CCS helped me at the hospital. They gave me their card, and they later contacted me.”*

*“The hospital social worker set up the referrals. The high-risk nurse from GGRC came to my house within a week.”*

#### *Families said:*

- Hospital social workers made those referrals, and agencies connected with families while they were in the hospital.

#### *Professionals added:*

- Some agencies participate in NICU and nursery rounds to help identify families quickly, and begin to talk with parents about agencies that assist.
- Professionals added that meeting with families while in the hospital is an important relationship-building step. After they leave the hospital, families are more likely to remember the contact and the services discussed.

**For those children with conditions that were identified later, parents received information from others in the community.**

#### *Families said:*

- Other parents, providers, and the family resource center helped families connect to the appropriate agency
- Some doctors told families who they could call, or called on their behalf
- Some families had case managers who told them about other services

#### *Professionals added:*

- Social workers and case managers are able to help families access programs because they have a good knowledge of resources
- Connecting families to the family resource center is very helpful; they can connect families to resources, especially alternative services and resources

**Everyone agreed that that it was helpful to hear about services and supports from people who speak the language of the family. Families said that receiving materials in their native language was extremely helpful.**

### What could be better?

**Many families said they felt like they were on their own in the beginning. Parents who cannot look for services on their own need assistance.**

*“Feeling helpless is the worst. Families need information.”*

*“When you are a first time parent, you don’t really know what to look for.”*

*Families said:*

- Parents said they have to seek out resources There is no organized way to find out about services.
- Some families said they found out about a service by coincidence, or in a random way.

**There are delays from the time a parent suspects their child has special need to the time they actually receive services.**

*“We have to wait to get referred, and then we have to wait again for services. Waiting is very stressful and frustrating.”*

*“Early intervention is very important – these are critical times in a child’s life. Early services are so beneficial. The loss of time can cause more problems, and also more severe delays.”*

*Families said:*

- Many parents spoke of suspecting “something was not right”, and being told by their physician that they should wait and see if the child “grows out of it”.
- Once the physician agrees that the child may have a delay, there can be a few months of testing before a referral is made. Once the referral is made, services may not begin for another 45 days or more, depending on the agency.
- Some families were referred to one agency, only to learn later that they should have gone to another agency. This caused delays in their children receiving services.
- A few families spoke of delays in getting responses from agencies once the referral was made; sometimes paperwork was lost or phone calls not returned.

*Professionals added:*

*“Our systems can overwhelm families – there are many different people from many different agencies.”*

*“Families’ whose lives are scattered sometimes don’t make it into the system.”*

- Once referred, families may need someone to help with the follow-up, or help them understand the paperwork.

**How can it be improved?**

**Organized information for families in all hospitals, and all pediatricians and obstetricians offices**

*Families said:*

- Information and resources on specific conditions should be provided at the time of diagnosis, or as quickly as possible
- Parents of premature babies should receive information on development, the infancy period, and support groups
- Early referrals to Family Resource Centers
- At regular check-ups, physicians asking more questions, spending more time with families
- All information provided in a brief, easy-to-understand format, in the family’s native language

**Individualized assistance to help families find the appropriate agencies and resources**

*“Having someone to tell you that you qualify for this, this and this...explaining the information very well and passing along all of the correct information to us.”*

*Families said:*

- A checklist with the agencies listed, a brief explanation of what they do, and the services available

*Professionals added:*

- Discharge workers/planners at each hospital to make referrals and help families begin to understand the system
- A central number (like an 800 number) for families to call for information and begin the referral process
- Someone to advocate for every family – to help them through the process, access available resources, spend time getting to know the family and their goals, and connect them to a parent mentor.
- Some families want to hear about all of the appropriate agencies and services at one time. Multiple phone calls and appointments can be time-consuming and cumbersome. Some families, however, prefer that information is given to them in a slower manner, and may need to have a trusting relationship with the person who is helping them access services.

*Professionals also suggested:*

**A system for follow-through on referrals to agencies**

- An automatic system to make sure each referral is followed up to completion. For example, if a letter is sent out and the family has not responded by specified date, someone calls the family to follow-up and answer any questions. (CCS eligibility workers have a similar system, and send out letters and make follow-up phone calls in the family's native language.)
- Communication between agencies communicating regarding the referrals they have accepted and those that are not eligible.

**Additional resources and services for those children who have severe conditions, but do not meet the criteria for GGRC or SFUSD (for example, mental health services).**

# The Process of Assessment

(How are children assessed, and how helpful is the process?)

## What works well?

**Families reported that once the initial assessment was complete, the information was very helpful.**

- Several parents reported that assessments for early intervention services from GGRC and SFUSD were very straightforward, and that the findings were very useful. Some of these families had the assessment conducted in their home.
- A few families mentioned that a team from SFUSD had assessed their child, which was especially helpful.
- Several families spoke of receiving assessments by physicians, and then being referred to CCS or GGRC for services

*Professionals added:*

**Assessments are best when they are done in comfortable settings, and are very valuable to families when the reports are “written in plain English, for the parent, to the parent.”**

- Some professionals reported that it was especially helpful to have time to meet with the family to explain the outcomes of the assessment, and then review the recommendations on a regular basis to make sure they are still relevant.
- In some cases, multiple assessments can help in understanding the child’s situation

**Assessments occur for children transitioning from early intervention to the school district because children are already in a system that facilitates the transfer.**

**Professionals conducting assessments reported success when they were able to follow through the assessment and attend the IEP meeting with the family. This is “time consuming and limits a program’s capacity, but it helps the family get the services that are necessary.”**

## What could be better?

**Some families reported that some of the assessments seem redundant.**

*“Our assessment from GGRC was very helpful. We also had assessments through CCS and the infant program, which didn’t seem necessary”.*

*“It would help if agencies could agree on one report that would meet all of the agencies needs”.*

- Many professionals agreed that the multiple assessments should be streamlined in an effort to help the families get services and treatment as soon as possible.

**There can be delays in conducting assessments and sharing the reports.**

*Families said:*

- Some families reported confusion over the paperwork necessary to get an assessment. If the paperwork is not complete, the assessment cannot be done.
- The school district does not conduct assessments over the summer, which can cause delays in receiving services for some children.

*Professionals added:*

- Assessment reports are sometimes not available and shared in a timely manner, and this varies from agency to agency
- There is a shortage of trained professionals to conduct assessments for very young children.
- Staff need to be well-versed in assessment skills, the various tools and an array of treatment options
- Assessors are needed to be able to conduct assessments in the family's native language, with an understanding of the family's culture.
- Time is needed to establish a rapport with the child and family, and develop the best approach for assessment. This is difficult to do when agencies are short-staffed, and demands are high.
- Some assessors are not aware of all of the referral sources (for example, medical personnel may not be aware of behavioral resources)

**Families reported concerns about the availability of services once the assessment was completed.**

- Some families mentioned pre-school placements that were not close to their home
- Other families reported delays in receiving speech assessments, and wanting more hours of speech therapy

**How can it be improved?**

**Agencies accepting reports from others and agreeing on one report that meets the needs of all of the agencies**

*Families said:*

- Agencies using assessments results from the agencies/individuals who know the child best.

*Professionals agreed, and added:*

- An assessment protocol that solves the needs of the multiple agencies
- A generalized assessment report form to record the findings, used by all agencies

*Professionals also suggested:*

**A dedicated pre-school assessment unit for the school district**

**Interagency trainings where each agency can share information on their assessment process and requirements, so that reports can be written in a manner that can be used by all agencies.**

# Coordination of Services, Within and Between Agencies

(How do agencies communicate with families and with each other about a child's care?)

## What works well?

### Good communication with case managers

*"My former social worker called me a lot to see if things are okay. "*

*"I had a good social worker and good services"*

- Many families reported feeling comfortable calling their case manager when they have questions
- Families stressed the importance of building a relationship with case managers, and making sure that they understand the family's needs
- Many families talked about how hard case managers work to help families, and appreciated what they do

### Involving all of the Professionals

*"I had a meeting at my house and we decided that the best way to exchange information was by e-mail, through a listserv. The messages are sent in English, and my interpreter, who is on the listserv, translates the messages into Spanish for me."*

- Families shared examples of agencies working together, coordinating their child's care:
  - One parent mentioned the 6-month follow-up clinic from the NICU as a place where services were coordinated, and everyone involved talked about her child's development, services next steps, etc.
  - Others talked about IFSP meetings where the school district, GGRC, provider, therapists, etc. sit down and write goals, as well as reviews
  - A few parents mentioned CCS team meetings at the Medical Therapy Program
- Providers and teachers all working together to talk with the parent about the focus of services and any changes that may be needed
- Several parents mentioned the caring school personnel who are involved in helping their child make progress. Parents spoke highly of staff knowledge in working with children with special needs.

#### *Professionals added:*

- Having a family specialist to coordinate between all of the different agencies with a family
- Having HRIIC available to bring all of the various agencies together
- Within CCS, new referrals are getting to the therapy team quickly. Families are given choices and identify sites with the best access for them. Taxi vouchers are provided, if required/needed, and families are matched with the language capacity required.

#### *Professionals also added:*

### Sharing of resources between agencies

- Agency members valuing each other's expertise
- Each agency being knowledgeable of the scope of work of other agencies and having trust in one another
- HRIIC trainings for parents and professionals

## What could be better?

### Supports change for many families when their child turns three.

*“After your child turns three, it seems like you have to call more to get help”.*

- Many families talked about the need for case managers when children turned three, and are no longer eligible for GGRC
- Private pre-schools are not easy to find, even when you have organizations to help you

#### *Professionals added:*

- Transition from early intervention to pre-school is confusing and some families don't understand where they are in the process

### The system has a limited capacity and caseloads are full

#### *Families said:*

- Case managers have high caseloads and some families reported that they have to call their case manager when they need something. They would prefer that the case managers have more time so that they could check on them from time to time.
- Several parents mentioned language barriers in talking with professionals. They expressed frustration at not being understood. Monolingual, non-English speaking families reported having difficulties speaking to agency supervisors when the supervisors do not speak the family's language.

#### *Professionals added:*

- Dealing with young children with special needs is a specialty. Staff with expertise in early childhood and various language and cultural competencies is needed. Recruitment can be difficult.

### Several parents reported quitting their job so that they could coordinate their child's care.

- Families reported multiple professionals involved in their child's lives. Making phone calls, going to medical appointments, researching services or therapies, and visiting programs can take a lot of time.
- In one focus group, families listed the different professionals involved in their child's care. Three parents had at least 10 different people involved in their child's regular care; another had 8 people involved, one had 5, and two had one.

### Coordinating services between agencies and health plans can be difficult.

- Some families mentioned not being sure what their insurance plan covered, and being confused by the paperwork.

#### *Professionals added:*

- Some families don't understand that they don't have to use their health insurance benefits before they apply for services
- Some families don't know what agencies they are connected to
- Sometimes private insurers refer the family to a public agency rather than paying for the service that is covered in the family's plan. (for example, equipment and therapies)

## How can it be improved?

**All of the agencies communicating well, all of the time, around specific children, and in general**

*“It would be great if all of the agencies got together, shared information and coordinated care for my child”*

- Some families saw the role of case manager as key, and stressed that it was important for families to ask questions of their case manager, and develop a relationship with him/her.
- After age 3, children should continue to have service coordination.

*Professionals added:*

- Centralizing communication – “fewer people and hands in the pot”
- A multi-disciplinary approach to case management
- Ongoing information-sharing between agencies

*Professionals also said:*

**A system to help those children who fall through the cracks... “learning about the cracks and how to get through them”**

- Getting to know the primary care provider, because sometimes they are the only professionals involved
- Regular training for primary care providers to help them understand the resources in the community and how to make referrals



The High Risk Infant Interagency Council (HRIIC) is an interagency parent/professional organization with the mission to ensure that all children with special health care needs, aged birth through five, receive services in a timely and coordinated manner, through interagency collaboration. HRIIC is composed of representatives of agencies and organizations, public and private, who provide services to high-risk infants and young children, and the parents of these children.



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