

Family Resource Centers Network of California
ADD Planning Grant

Summary Stakeholder Report

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INTRODUCTION

Parent-directed Family Resource Centers funded by the Early Start system are unique to California. Developed in the early 1990s during the planning years of Part H 99-457, the Family Resource Centers (FRCs) were formally authorized by the California Legislature in 1997 with the passing of SB 1085. All Early Start Family Resource Centers provide information, education and parent-to-parent support services to promote access to early intervention services for children who have, or are at risk of, developmental disabilities. All FRCs serve families with children birth to age three; others have additional funding that allows them to provide services to a broader population, i.e., older children and youth.

The Family Resource Centers Network of California (FRCNCA) received a grant from the Administration on Development Disabilities (ADD) to build the capacity of Early Start Family Resource Centers (FRC) statewide. The grant presents an opportunity to learn how FRCs could better serve families and partner more effectively with other family support agencies and providers through focus groups, surveys and organizational assessments. The FRCNCA Steering Committee will use this information to create a strategic plan that supports all FRCs to strengthen services, and expand and enhance its partnerships on behalf of children, youth and adults with developmental disabilities in California.

Methodology

The FRCNCA developed a two-pronged process for assessing its existing network of services and partnerships, by asking for input from families and from professionals:

- Focus Groups with Families:
 - Family Resource Centers are divided into nine regions. Each of the nine regions was asked to conduct a single focus group with parents with children with disabilities. Regions 4 through 9 were also asked to conduct an additional focus group with Spanish-speaking parents with children with disabilities. (Demographic data suggested that non-English-speaking parents comprised a portion of the families in all regions. Resources were not available to conduct focus groups in languages other than English and Spanish.) A total of 15 focus groups were conducted. Each region received a stipend for its work; all focus group participants received stipends as well.
 - At the focus groups, participants were asked to fill out a brief questionnaire and to participate in a discussion.
 - A total of 156 families, 92 English-speaking and 64 Spanish-speaking, including mothers and fathers, participated in the focus groups. (Please see **Appendix A** for a complete description of focus group participants.)
- Questionnaire for Professionals:
 - Each of the 52 Family Resource Centers was asked to distribute a questionnaire to three to five partner family support agencies or providers. The types of partners they chose could have included California Children's Services, Hospitals, Regional Centers, Educators, Doctors, Health Clinics, Social Service Agencies, First 5 Commissions, Early Head Start,

Child Care Settings (Centers and Family Child Care Homes), Child Care Resource and Referral Agencies.

- Fifty-seven (22% of the potential number distributed) questionnaires were returned. (Please see **Appendix B** for a breakdown of questionnaires returned by region.)

Report Organization

This summary report is organized into three sections:

- Overall Themes
- Focus Group Findings
- Professional Questionnaire Findings

I. OVERALL THEMES

This section of the summary report presents overall themes that were most frequently raised across all stakeholder participants.

Information & Education

For Parents:

- Information about recreational activities
- Ongoing information, through the mail and other means, about support groups, mentoring and opportunities to network with other parents
- Information about sibling support groups and sib shops
- Up-to-date information and research on disabilities of interest to parents, as well as the likely range of therapies and interventions
- Current information about and referrals to service providers (e.g., therapists, psychologists, family counselors, doctors, specialized providers)
- Assistance in understanding and navigating the system, as well as completing necessary paperwork (e.g., SSI, IHSS, special education, regional centers)
- Information about educational options for children with disabilities, as well as educational approaches

For Professionals:

- Training on how to work with children with special health care needs and their parents, including a better understanding of the challenges families face
- Information about services and resources in the community

Parent-to-Parent Support

- Support groups (e.g., disability and non-disability specific, with child care, in multiple languages, at convenient times)
- Activities for the whole family, including siblings (e.g., sports, recreation, camping)
- Social activities (e.g., organize around meals, include child care)

Other Activities & Support

- Expand access to FRC services and continue supports beyond age 3
- Increase advocacy on behalf of families (e.g., child care inclusion, ADA compliance, IEPs)
- Create more opportunities to collaborate formally and informally with other providers

Outreach & Awareness

- Continue direct mailings (e.g., flyers, newsletters, monthly calendars)
- Distribute information through schools (e.g., flyers, school mailings, integration into in-service trainings)
- Connect with hospitals, pediatricians and other medical professionals (e.g., therapists, case managers, speech pathologists)
- Establish contacts with other community service organizations and agencies that serve families and children (e.g., attend inter-agency meetings, visit organizations with literature, conduct collaborative outreach)

II. FOCUS GROUP FINDINGS

This section of the summary report presents the findings from the focus groups with families, including:

- Ease in accessing services;
- Services they find most and least helpful;
- Information and education needs (for families and for professionals);
- Parent-to-parent support needs;
- Other service and support needs; and
- Outreach and awareness methods.

Service Access

143 (92%) focus group participants reported that they could easily access Family Resource Center (FRCs) services. Of the remaining 8%, 6% did not respond to the question and 2% said that they could not easily access services. Of that 2%, suggestions included keeping the FRC open later in the evening and consistently returning phone calls.

Most Helpful Services

Many of the focus group participants had used Family Resource Center services frequently. Fifty percent of English-speaking families and 57% of Spanish-speaking families had used FRC services more than five times in the past year.

Support groups (56%), library (51%), educational events (49%), phone line/warmline (42%), and information dissemination (39%) topped the list of services that focus group participants found most helpful. (See Table 1 for full results.)

Fewer Spanish-speaking families than English-speaking families (30% vs. 46%), however, responded that information dissemination was the most helpful service. This finding was also true for special family events (22% vs. 38%) and drop-in services (13% vs. 24%). More Spanish-speaking families than English-speaking (39% vs. 14%) did find satellite services and home visits most helpful. Spanish-speaking families also found support groups helpful at a higher rate than English-speaking families (67% vs. 48%).

Other helpful services that families noted include: referrals to services; advice and counseling; recreational activities; child care; employment with the FRC; IFSP/IEP support; medical binders; and Town Hall meetings with schools.

Table 1: Most Helpful Services

Service	English		Spanish		Total	
	#	%	#	%	#	%
Support Groups	44	48%	43	67%	87	56%
Library	45	49%	34	53%	79	51%
Educational Events	47	51%	30	47%	77	49%
Phone Line/Warmline	34	37%	31	48%	65	42%
Information Dissemination	42	46%	19	30%	61	39%
Special Family Events	35	38%	14	22%	49	31%
Parent Mentor	24	26%	20	31%	44	28%
Focus Groups	20	22%	19	30%	39	25%
Satellite/Home Visits	13	14%	25	39%	38	24%
Drop-In	24	26%	13	20%	37	24%
Outreach	12	13%	17	26%	29	19%
Parent Teams	9	10%	9	14%	18	12%
Fundraising	14	15%	2	3%	16	10%
Assistive Tech Lab	5	5%	2	3%	7	4%
Other	14	15%	3	5%	17	11%
Not Applicable	10	11%	6	9%	16	10%
No Response	4	4%	5	8%	9	6%

Least Helpful Services

A significant percentage of participants (64%) did not reply to the question because they had either not used FRC services before or believed that all of the services they had used were helpful.

Assistive Tech Lab (10%), satellite/home visits (6%), and fundraising (6%) were the services that participants most frequently noted as “least helpful.” See Table 2 for full results.

Participants provided the most substantive comments about how to improve library services. They asked that materials be more comprehensive (e.g., inclusive of a broad range of disabilities) and that they be updated frequently.

Table 2: Least Helpful Services

Service	English		Spanish		Total	
	#	%	#	%	#	%
Assistive Tech Lab	10	11%	5	8%	15	10%
Satellite/Home Visits	5	5%	5	8%	10	6%
Fundraising	3	3%	7	11%	10	6%
Phone Line/Warmline	2	2%	3	5%	5	3%
Library	4	4%	1	2%	5	3%
Outreach	3	3%	0	0%	3	2%
Parent Mentor	3	3%	0	0%	3	2%
Parent Teams	3	3%	0	0%	3	2%
Support Groups	2	2%	1	2%	3	2%
Drop-In	2	2%	0	0%	2	1%
Special Family Events	1	1%	1	2%	2	1%
Educational Events	1	1%	0	0%	1	.6%
Information Dissemination	1	1%	0	0%	1	.6%
Focus Groups	0	0%	0	0%	0	0%
Other	0	0%	0	0%	0	0%
Not Applicable	10	11%	6	9%	16	10%
No Response	48	52%	36	56%	84	54%

Information & Education

Seventy-one percent of participants replied to the question about information on the questionnaire, and 63% replied to the question about educational activities. Of those who responded, a handful replied that they did not know what information they needed, or that they needed nothing more from FRCs.

Accessing information about family counseling and psychotherapy was a significant theme for Spanish-speaking respondents. They also emphasized information about recreation activities, more educational opportunities for the whole family, sign language classes, and more educational opportunities in Spanish.

Those who responded to the questionnaire and focus group participants suggested the following:

- Information about recreational activities (23)
 - Summer camps (e.g., for children and for the whole family)
 - Sports (e.g., for children and for the whole family)
 - Art classes
 - Music classes
 - Activities for school-age kids

- Ongoing information, through the mail and other means, about support groups, mentoring and opportunities to network with other parents (21)
 - Such as, sign language support group
- Information about sibling support groups and sib shops (20)
- Up-to-date information and research on disabilities of interest to parents, as well as the likely range of therapies and interventions (20)

Formats:

- Training videos
- Information on the computer
- Newsletter articles
- Books on tape
- Workshops
- Resource fairs
- On-line classes and bulletin boards
- Up-to-date library materials in various languages

Topics:

- Discipline and behavior interventions
 - Speech
 - Sensory integration
 - Children with multiple disabilities
 - Premature, sickle-cell anemia
 - Autism
 - Down Syndrome
 - Cerebral Palsy
 - Nutrition
- Current information about and referrals to service providers (e.g., therapists, psychologists, family counselors, doctors, specialized providers) (18)
 - Offer perspectives from other parents about “who is good”
 - Information about educational options for children with disabilities, as well as educational approaches (18)
 - More information about school transportation options
 - Presentations from school personnel to explain the terminology used in the different assessment tests
 - How to work with teachers to ensure your child’s educational needs are met
 - Assistance finding inclusive child care, after-school care and respite care (14)
 - Sign language classes (13)
 - In Spanish
 - Offer more conferences, trainings and workshops, as well as information about workshops offered by others (12)

- More presentations by professionals and experts on topics of interest to parents (including those who speak Spanish)
- Short workshops (e.g., no more than two hours)
- Offer child care
- Assistance in understanding and navigating the system, as well as completing necessary paperwork (e.g., laws and regulations, SSI, Regional Centers, IEPs, CCS, IHSS, Alta) (10)
 - How to talk to therapists and other professionals
- Information and educational opportunities for the extended family (e.g., siblings, grandparents, etc.) (9)
- IEP support and training (8)
 - Train more parents and others to accompany parents to IEP meetings
- Information about playgroups (7)
 - With typically developing children
 - Organized by age or disability
 - Incorporate Tech toys
- Trainings to help parents anticipate and plan for the next steps in their child's development (5)
 - Assistance making transitions from one system or school to another
- Information for parents with newly diagnosed children (5)
 - Provide information and support in the NICU
 - Create a pamphlet on what to do when you first find out your child has a disability
- Trainings for professionals (4)
- Tutoring support and homework assistance (4)
- Translating all information into parent-friendly formats (2)
- Financial aid (2) (e.g., for summer camps, etc.)
- Educational activities to help boost children's understanding of their disabilities and self-esteem (2)
- Assistance accepting child's disability (2)
- Assistance preparing my child for peer interaction (2)
- More resources to check-out (e.g., computer software like Mayer Johnson and/or flash cards for ABA programs) (1)
- Places to get equipment (1)
- Information about wills, trusts and estate planning (1)
- Seminars on how to do your taxes (1)
- Workshops to gain employment skills (1)
- Assistance learning English (1)

Medical Professionals

Fifty-eight percent of focus group participants responded to this question on the questionnaire. The responses from Spanish-speaking and English-speaking families were very similar. Focus group participants suggested that medical professionals be provided with the following:

- Training on how to work with children with special health care needs and their parents, including a better understanding of the challenges families face (17)

Formats:

- Use parent panels
- Create networking opportunities

Specific Issues:

- Spend more time with children
- Be more sensitive and patient
- Treat parent as part of the team and listen to their perspective
- Understand that our children cannot wait for long periods for appointments
- Provide detailed information about the diagnosis and the disability
- Have the equipment needed (e.g., appropriate scales for older children in wheelchairs)
- Information about services for children with disabilities and their parents (13)
- Information about FRC services (11)
 - Supply them with brochures that they can distribute
- Better education on disabilities (e.g., Fragile X Syndrome, Autism, Cerebral Palsy, Down Syndrome) (11)
 - Refer doctors to educational programs related to disabilities
 - Encourage doctors and genetic counselors to provide all the facts about disabilities rather than pushing women to terminate a pregnancy

Case Managers/Service Coordinators

Forty-three percent of focus group participants responded to this question on the questionnaire. The responses from Spanish-speaking and English-speaking families were very similar. Focus group participants suggested that case managers/service coordinators be provided with the following:

- Information about services for children with disabilities and their parents (10)
- Training on how to work with children with special health care needs and their parents, including a better understanding of the challenges families face (7)
 - Training on the importance of consistent communication and support
 - Treat parent as part of the team and listen to their perspective
 - Be proactive instead of reactive
 - Training on helping parents manage and coordinate appointments and services
 - Training on helping parents with IEPs
- Information about FRC services (7)
 - Encourage parents to call, even without a diagnosis

- Advocacy training (4)
- Better education on disabilities (2)
- Assistance with Spanish interpretation (2)
- Support to pursue continuing education (2)
 - Encourage advanced training and degrees
 - Provide information on financial supports for continuing education
 - Provide information about workshops
- Training on medical logs and how to use them (1)

Therapists

Thirty-six percent of focus group participants responded to this question on the questionnaire. Focus group participants suggested that therapists be provided with the following:

- Better education on disabilities and different kinds of therapies (e.g., music, art, sensory integration, alternative speech therapies) (13)
 - Provide therapy resource pamphlets
 - Provide networking opportunities
- Training on how to work with children with special health care needs and their parents, including a better understanding of the challenges families face (8)
 - Treat parent as part of the team and listen to their perspective
 - Spend more time with the children
 - Provide detailed information about progress and recommendations on other services needed; explain observations and recommendations in language parents understand
- Information about FRC services (5)

- Information about services for children with disabilities and their parents (4)
 - Provide up-to-date information about support groups
- Assistance with Spanish interpretation (3)

The responses from Spanish-speaking and English-speaking families were very similar, however, a number of Spanish-speaking families were interested in alternative speech therapies for children who are unable to speak.

Educators

Forty-six percent of focus group participants responded to this question on the questionnaire. Focus group participants suggested that educators be provided with the following:

- Training for teachers on how to work with children with special health care needs and their parents, including a better understanding of the challenges families face (17)
 - Training on effective communication with parents (e.g., daily and monthly communication)
 - Treat parent as part of the team and listen to their perspective
 - Training on developing effective IEPs
 - Training on providing educational methods tailored and responsive to each child's needs
 - Networking opportunities
- Better education on disabilities and related laws (14)
 - Information about the laws
 - Provide through in-service trainings and staff meetings
 - Provide information on how to include a child with special needs and who is responsible for what
- Information about services for children with disabilities and their parents (6)
 - Provide through in-service trainings and staff meetings
- Information about FRC services (6)
- Training for teaching assistants (5)
- Assistance with Spanish interpretation (1)

The responses from Spanish-speaking and English-speaking families were very similar, however, a number of Spanish-speaking families mentioned training for teachers' assistants, as well as teachers.

Other Groups

Twenty-eight percent of focus group participants responded to this question on the questionnaire. Focus group participants suggested providing training in disability awareness and in the experiences of families with children with special health care needs to the following groups¹:

- School bus drivers (5)
- General public (4)

¹ Although 43 participants responded to this question, many of them replied to this question with ideas about other services and resources they need, rather than other groups that need to be educated. Their responses were shifted to the section of the report regarding other services and resources.

- Child care, after-school care, and respite care settings (4)
- Employers (2)
- Churches (2)

Other groups suggested in focus group discussions include:

- Service clubs
- Police and fire departments
- Parenting groups
- Extended family members
- Media

The responses from Spanish-speaking and English-speaking families were very similar, however, a number of Spanish-speaking families mentioned training for school bus drivers.

Parent-to-Parent Support

Forty-six percent of participants, 45% English-speaking and 47% Spanish-speaking, responded that they would like support in networking with other parents. In both the questionnaires and focus group discussion, they suggested the following types of supports and opportunities:

- More support groups (31)
 - Opportunities to vent
 - Disability and non-disability specific
 - Child care provided
 - Supports for dads
- Activities for the whole family, including siblings (11)
 - Sports and sports leagues
 - Recreational activities
- Social gatherings (7)
 - Consider centering activities around meals (e.g., picnics)
 - Organize camping trips
 - Make all activities more accessible to families in the community
- Better parent-to-parent matching with all activities (5)
 - Similar age children
 - Disability specific
 - Children born prematurely
 - Matching parents of higher functioning children
- More mentoring and mentor training (3)
 - Help with paperwork

- More playgroups (3)
 - For all age groups
 - Integrated with typically functioning children
- Emergency phone line for after hours (1)
- Phone buddies (1)
 - With phone cards to support long-distance relationships

Spanish-speaking families mentioned social and recreational activities more frequently; English-speaking families suggested support groups and mentoring more frequently.

Of the remaining 54% of participants:

- 34% percent of participants said they like parent-to-parent support, but are satisfied with the support they have;
- 19% did not respond to the question; and
- 1% said they would not like support in networking with others.

Other Activities & Support

Sixty-three percent of focus group participants responded to this question on the questionnaire. Focus group participants suggested the following²:

- Continuing supports through age 21 (22)
 - Expand Early Start home visits beyond age 3
 - Assist families to transition when they are no longer eligible for supports
- Assistance in advocating for more supports for low-incidence and medically fragile children (e.g., case management, advocacy, respite etc.) (10)
- Increase personal follow-up for all families after they have accessed services or supports (8)
- Provision of free or low-cost child care services, particularly while parents are visiting FRCs (7)
- Provide access to all FRC supports and services in Spanish
- Assistance in advocating for more bilingual supports in other service areas (e.g., case management, therapy, medical services, etc.) (7)
- Assistance creating connection and collaboration amongst families and service providers, especially to assist with transitions (5)
- Assistance in advocating to include cameras on school buses (4)
- Transportation support (3)
- Access to advocates and advocacy support (3)
- Provision of music appreciation therapy through FRCs (3)

² Many respondents re-iterated their desires for increased information, education, and peer support. Since those have been captured in other sections, this section highlights activities and supports that do not fall into those areas.

- Increased access to equipment (3)
 - Offer more equipment for family use
 - Organize equipment swaps among families
- Provision of car seats for children under age 3 (3)
- Provision of special formulas for children under age 3 (2)
- More opportunities to access physical therapy (2)
 - Develop a center where we could take our kids daily to learn how to work with them and/or have physical therapists/occupational therapists on hand to help
- Access to case managers through FRCs (2)
- More contact with resource parents and parent representatives (2)
- More public disability awareness efforts, especially for communities of color (e.g., African American, Latino) (2)
- Assistance in encouraging more parents to be active in sharing experiences with special needs, including those with older children (2)
- Assistance in advocating for our children to have their own school (2)
- More satellite locations (1) (e.g., Watsonville)
- Increased supports at military bases (1)
- More volunteer and community services opportunities for parents (1)
- One-stop shop for services (1)
- Assistance in finding employment (1)
- Opportunities for children with disabilities to network with college students so that they can encourage our children to continue going to school (1)

Spanish-speaking families emphasized continuing services throughout the lifespan, assistance for low-incidence children, collaboration between parents and services providers, and creating more opportunities for supports and services provided in Spanish.

Outreach & Awareness

Thirty-five percent of participants did not respond to this question on the questionnaire (39% of English-speaking respondents and 30% of Spanish-speaking). Ideas that emerged in the completed questionnaires and focus group discussions included:

- Continue direct mailings (17)
 - Flyers
 - Newsletters
 - Information bulletin or monthly calendar

- Distribute information through schools (16)
 - Flyers
 - Integration into in-service trainings
 - PTA meetings
- Connect with hospitals, pediatricians and other medical professionals (e.g., therapists, case managers, speech pathologists) (14)
 - Network with NICUs
 - Ensure that information is sent home with every new baby
 - Posters to hang in doctors' offices
 - Co-locate FRC services in hospitals
- Advertise through the media (e.g., cable, radio, newspaper, television, magazines, billboards) (13)
- Network through community-based settings (e.g., service clubs, libraries, churches, child development settings, laundry mats, community events) (10)
- Host meetings and social activities (9)
- Continue phone calls to parents (8)
 - Use parent volunteers to call parents
- Utilize the website (8)
- Establish contacts with community service organizations (7)
 - Co-locate FRC services with community services (e.g., WIC)
- Create and distribute comprehensive information on Family Resource Center services (6)
 - Mailings and ambassadors
 - Send out every 6 months
- Distribute surveys and questionnaires to parents (6)
- Rely on parents to spread the word about services (e.g., word of mouth) (5)
- Target outreach and training to organizations that work with families with children with disabilities (3)
 - Create a volunteer network of families to disseminate information to providers
 - Create Speaker's Bureau
- Establish more Spanish-speaking representatives to reach Hispanics who are not aware of Family Resource Center services (1)
- Utilize a universal release of information form to facilitate referrals to FRCs (1)
- Create liaisons with policy makers (1)

Spanish-speaking families emphasized hosting meetings, distributing mailings, continuing phone calls and sending out surveys.

III. PROFESSIONAL QUESTIONNAIRE FINDINGS

This section of the report presents the findings from the professional questionnaire, including:

- FRC strengths and areas for improvement;
- Information and education needs (for professionals and for families);
- Parent-to-parent support needs;
- Other support needs; and
- Outreach and awareness methods.

One hundred percent of professional questionnaire respondents replied that they have worked with FRCs. They have worked together in the following ways:

- Distribute information about and refer clients to each other's programs (26)
- Service coordination and joint service delivery (e.g., outreach, parent education, support groups, home visits, IFSP home visits, IEP and IFSP meetings, parent/teacher training, teen groups, assistive technology workshops) (24)
- Work on inter-agency teams and committees together (19)
- Information and resource sharing (16)
 - Access FRC libraries
 - Borrow one another's materials
 - Discuss family issues and needs
- Joint presentations and special events planning (e.g., information fairs) (9)
- Formal liaisons, co-location or contracts with partner organizations (5)
- FRC provides binders for our families to organize information such as IFSP, medical records, photos, memories, etc. (2)
- Joint project planning and implementation (1)
- Joint funding proposals (1)
- FRC provides information on disabilities (1)
- FRC distributes information about partner organization and its activities (1)
- Joint intake (1)
- Collaboration on school meetings to ensure appropriate classroom placement and other IEP issues (1)

FRC Strengths

Professional questionnaire respondents noted the following among the things they liked best about working with FRCs:

- Exemplary staff (e.g., expertise, enthusiasm, commitment, flexibility, caring, compassion, creativity, willingness, candor about issues and barriers, responsiveness, thoroughness, well-versed in laws and regulations, knowledgeable about resources, out-of-the-box thinking, little staff turnover, strong follow up, Spanish-speaking, reflective of people serving, organizational skills, professionalism) (20)
- High quality, comprehensive services for families (15)
 - Invaluable information and support for parents and siblings
 - Connections to needed resources
 - Parent perspective always kept in mind
 - Connection with other parents with similar needs and perspectives
 - Library resources
- Strong coordination and collaboration with partners (10)
- Responsive to partners and open to feedback (10)
 - Approach partners as participants in fulfilling a common goal
- Information sharing with and trainings for partners (5)
 - Great newsletters
- Accessible locations (3)
- Positive in relationship with the schools (2)
 - Assist with smooth transitions for families and children.
- Excellent outreach to the Spanish-speaking community and assistance with translation (2)
- Family binder (1)

FRC Areas for Improvement

Forty-four percent of professional questionnaire respondents replied that there was nothing they liked least about working with FRCs. One person responded that he or she had not been in the position long enough to respond and another gave no response at all. The remainder noted the following areas for improvement:

- Limited funding for FRCs (9)
 - Limited availability of services to meet community needs, particularly in outlying areas
 - Staff are overworked and underpaid
 - Hours of service are limited
 - Library materials are out of date
 - Training for peer parents cannot take place
 - Eligible for services only through age 3
- At times, FRCs approach is adversarial (2)
- Some coordination and territorial issues (2)
- Communication issues (2)
 - Slow response time from management
 - Trouble with website
- Insufficient focus on issues related to deafness (1)
- Staff turnover (1)
- Limited outreach to programs (1)
- Expanded advocacy role for parents (1)
- Stronger relationship with public health nurses (1)
- More accessible location for FRC services (1)
- More operational independence for FRCs (1)
- Increased clinical supervision (or reflective supervision) for staff, especially parents working with other parents (1)

Information & Education

Forty-two percent of professional questionnaire respondents replied that FRCs were already providing them with the information they needed. Only seven percent replied that they needed nothing, and 5% gave no response at all. Respondents noted that they find the following information and education helpful:

- Information for professionals (e.g., service coordinators and staff in other partner organizations) on specific disabilities and how best to provide services to families in their care (13)

Formats:

- Resource library (keep partners up-to-date on resources in the library)
- Information packets
- In-service trainings
- Newsletter (hard copy and on-line)

Topics:

- More information related to deafness
 - Parent-centered care
 - Appropriate points of intervention
 - Experience of having a special needs child
 - Autism
 - IEPs
- Information about services and resources in the community (11)
 - Free or low-cost car seats
 - Transportation resources
 - Child care
 - Mommy and Me groups
 - Resources for families dealing with terminal illnesses
 - Disability-sensitive physicians
 - Information for professionals (e.g., service coordinators and staff in other partner organizations) about parent matching and support groups (9)
 - For children with Autism
 - Information about FRC services and upcoming events that we can distribute to parents (4)
 - Email updates
 - Event calendars
 - Brochures
 - In-service trainings
 - Political and budget updates for professionals (via meetings, email or newsletters) (1)

Parents

Professionals responded that parents could benefit from the following information and educational activities:

- Up-to-date information and research on disabilities, as well as the likely range of therapies and interventions (15)
 - Provide access to as much information as possible in different languages
 - Keep families up-to-date on new library resources

Formats:

- Books
- Videos
- Specific diagnosis packets
- Websites
- Workshops
- On-line bulletin board
- Short, informational meetings
- One-to-one communication

Topics:

- Autism
- Assistance in understanding and navigating the system, as well as completing necessary paperwork (e.g., SSI, IHSS, special education, regional centers) (13)
 - How to talk to therapists and other professionals
 - How to become skilled consumers of information (e.g., what questions to ask, how to evaluate information, etc.)
 - How to advocate for your child
- More workshops, trainings and conferences for parents (11)
 - Provide dedicated workshops for Spanish-speaking parents
 - Offer child care and scholarships for trainings and workshops

Topics:

- IEPs/IFSPs
- Transitions
- Parent notebook
- Inclusion
- Literacy
- Parenting information (8)
 - Positive discipline
 - Stress management
 - Parent's rights
 - Effective communication within the family
 - Dealing with terminal illness

- Current information about and referrals to service providers and resources (8)
- Ongoing information, through the mail and other means, about support groups, mentoring and opportunities to network with other parents (6)
- Assistance finding inclusive child care and respite care (6)

Parent-to-Parent Support

Ninety-one percent of participants responded to this question on the questionnaire. Professionals suggested that parents could benefit from the following parent-to-parent support activities:

- More support groups (14)
 - Talk to parents about how and when they would like to come together
 - Consider adding arts and crafts to support groups to relax families
 - Disability and non-disability specific
 - Groups for siblings
 - Provide child care
 - Coordinate transportation
 - Offer Spanish-speaking groups

Topics:

- Literacy
- Hard of hearing and deaf children
- Social gatherings and parties (9)
 - Block-party type events
 - Include babysitting
- Activities for the whole family, including siblings (8)
 - Field trips
 - Coordinate transportation
- Transportation assistance and carpooling (4)
- Informal phone support for families who speak multiple languages (4)
 - Parent-to-parent phone call to every newly diagnosed parent
- More mentoring and mentor training (3)
 - Create incentives
 - Peer parents
- More playgroups (2)
- Advice about helpful services and resources in the community (2)
- On-line groups and peer-to-peer connections (2)
- Buddies (2)
 - For parents transitioning programs or from home to hospital
 - Pairing up parents who can help each other in emergencies

- 24-hour hotline (1)
- Respite care (1)
- Assistance at IEP meetings (1)

Other Activities & Support

Twenty-five percent of professional questionnaire respondents replied that there was nothing more FRCs could do to support them. One person did not feel he or she could answer the question, and 18% gave no response at all. Respondents noted that they would like the following:

- Expand access to FRC services (8)
 - Provide supports and information for parents and providers at more convenient times.
 - Hire more staff
 - Bring more services to the outlying areas
 - Offer child care for families participating in FRC activities
 - Help families coordinate transportation
- Increase advocacy on behalf of families (7)
 - Advocate for more inclusive child care settings
 - Advocate on behalf of parents whose rights are violated under the ADA
 - Advocate regarding IEP's, especially at transitions times
- Create more opportunities to collaborate formally and informally with other providers (7)
 - FRC and the Early Intervention services provider team up for a joint visit during the first three months after diagnosis
 - Work together on helping families feel comfortable seeking professional help
 - FRC partners with other organizations to coordinate support groups for their families
 - Engage more with public agency staff
 - Conduct outreach collaboratively
 - Partner with other community-based Family Resource Centers (often funded through Promoting Safe and Stable Families and First Five)
- Expand outreach efforts (5)
 - Target hard-to-reach populations
 - Hire outreach staff that are culturally, linguistically and socio-economically competent
- Continue supports and services beyond age 3 (5)
- Provide parent notebooks and medical home binders (3)
- Offer scholarships for parents to participate in educational activities (2)
- Offer toy lending (1)
- Provide clinical supervision (or reflective supervision) to parents working with other parents (by a social worker or psychologist) (1)
- Provide interpretation and translation for Spanish-speaking families accessing other services and activities (1)
- Create more opportunities to share information with partners (1)

- Expand role clarity between service coordinators and FRC staff (1)
- Expand services and supports focused on deafness (1)
- Create support groups for teenagers with physical disabilities (1)
- Consider more support for parents with developmental disabilities a major area for future development (1)

Outreach & Awareness

Ninety-one percent of participants respond to this question on the questionnaire. Ideas that emerged included:

- Establish contacts with other community service organizations and agencies that serve families and children (23)
 - Attend meetings, particularly inter-agency meetings, and make presentations
 - Routine visits to organizations to meet staff and drop off FRC literature
 - Conduct collaborative outreach with other organizations (e.g., fairs, events)
 - Collaborate with related agencies and organizations
 - Include links to the FRC on other agencies' websites
 - Send monthly activity schedule for service coordinators and other providers
- Continue direct mailings and email updates (8)
 - Newsletters
 - Flyers
- Distribute information through schools (6)
 - Flyers
 - Notices home to families
- Hospitals, pediatricians and other medical professionals (5)
 - Flyers
 - Posters
 - Coordinate with regional centers to do in-person visits twice year
- Advertise through the media (e.g., cable, radio, newspaper, television, magazines, billboards) (5)
- Create and distribute comprehensive information on Family Resource Center services (3)
 - Brochures
- Network through community-based settings and events (e.g., libraries, child care settings, Chamber of Commerce) (3)
- Continue phone calls to parents (2)
- Launch a state-wide advertising campaign (1)
- Website (1)
- Create liaisons with elected officials (1)
 - Include FRC materials in their mailings

Appendix A: Description of Focus Group Sample

There were a total of 156 focus group participants, including 92 English-speaking and 64 Spanish-speaking.

Participant Breakdown by Region

Region 4 had the most participants between its two focus groups.

Region	English	Spanish	Total
1	5	0	5
2	15	0	15
3	9	0	9
4	17	15	32
5	8	13	21
6	7	6	13
7	11	11	22
8	8	8	16
9	12	11	23
TOTALS	92	64	156

Number of Children

Most of the participants had only one child with a special health care need or disability.

Number of Children	English	Spanish	Total Families	Total Children
1	76	57	133	133
2	10	6	16	32
3	5	1	6	18
6	1	0	1	6
TOTALS	92	64	156	189

Age of Children

Most of the focus group participants had children from 1 to 3 years or from 6 to 12 years of age.

Children's Age	Number of Children	Percent of Children
Under 1 year	11	6%
1 to 3 years	59	31%
4 to 5 years	18	10%
6 to 12 years	64	34%
13 to 18 years	23	12%
Over 18 years	14	7%
TOTALS	189	100%

Children's Needs and Disabilities

A number of families who participated in the focus group had children with Down Syndrome (20%) or Autism (19%). The next most frequently occurring disability among children of participants was Cerebral Palsy (11%).

Needs/Disability	Number of Children	Percent of Children
Autism Spectrum Disorders	2	1%
Attention Deficit/Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)	9	5%
Autism	36	19%
Blindness or eye disorders	4	2%
Cerebral Palsy	21	11%
Developmental Delay	7	4%
Down Syndrome	37	20%
Dyslexia	2	1%
Epilepsy	3	2%
Fetal Alcohol Syndrome	2	1%
Hearing loss or disorder	7	4%
Mental Retardation	7	4%
Pervasive Development Disorder Not Otherwise Specified	2	1%
Prader-Willi Syndrome	3	2%
Seizures	3	2%
Spina Bifida or spinal disorders	2	1%
Trisomy 13	2	1%
Turner Syndrome	2	1%
Other	12	6%

Service Utilization

Many of the focus group participants had used Family Resource Center services frequently. Fifty percent of English-speaking families and 57% of Spanish-speaking families had used FRC services more than five times in the past year.

Number of Times Used Service in the Last Year	English		Spanish	
	#	%	#	%
None	10	11%	6	9%
Once	11	12%	6	9%
Between 2 and 5 times	23	25%	15	23%
More than 5 times	19	21%	15	24%
More than 10 times	27	29%	21	33%
No Response	2	2%	1	2%
TOTALS	92	100%	64	100%

FRC Awareness

Most participants learned about FRCs through the Regional Center (19%), friends (10%) or local networks (9%). English-speaking participants most frequently learned about FRCs through Regional Centers and Spanish-speaking families most frequently learned through Early Start (14%)

Other ways participants learned about FRCs included: other services providers (e.g., WIC, CCS, Service Coordinators, Easter Seals, Case Managers), the internet, being involved in community groups and associations, and mailings.

Source of Information about FRC	English		Spanish		Total	
	#	%	#	%	#	%
Regional Center	21	23%	8	13%	29	19%
Friend/Parent/Co-Worker	8	9%	7	11%	15	10%
Local Parent Network or Support Group	9	10%	5	8%	14	9%
School/School District	12	13%	2	3%	14	9%
Early Start	4	4%	9	14%	13	8%
Hospital/Doctor	8	9%	4	6%	12	8%
Other FRC or FRCNCA	4	4%	4	6%	8	5%
Early Head Start/Head Start	0	0%	4	6%	4	3%
Therapist or Psychologist	3	3%	0	0%	3	2%
Other	6	7%	10	16%	16	10%
No Response	31	34%	16	25%	47	30%

Appendix B: Professional Questionnaire Responses by Region

A total of 57 professional questionnaires were returned.

Questionnaires Returned by Region

Region	Number of FRCs	Number of Professional Questionnaires Returned
1	6	6
2	5	6
3	8	5
4	4	2
5	3	7
6	9	9
7	14	12
8	2	8
9	1	2
TOTALS	52	57

