

BRAID Focus Groups
Report
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Overview

In 2018, the South Central Regional Center (SCLARC), in collaboration with the East Los Angeles Family Resource Center (ELAFRC), received funding through the Mental Health Services Act (MHSA) and the Department of Developmental Services (DDS), to develop services for 2 groups of parents: 1) parents of children 0-3 with a developmental disability and emotional/behavior challenge and 2) parents who are regional center consumers who have children 0-3. It was proposed to conduct a total of four focus groups to inform the development programs that met the needs and preferences of parents. There would be two focus groups for parents of children 0-3 with a developmental disability and emotional/behavior challenge (one focus group for SCLARC parents and one for ELAFRC parents) and two focus groups for parents who were regional center consumers who had children 0-3 (one focus group for SCLARC parents and one for ELAFRC parents). Fran Goldfarb was contracted to develop the focus group questions, conduct the focus groups and develop the report.

Each entity was responsible for recruiting participants for the focus groups in their area. The focus groups for Priority 1) parents of children 0-3 with a developmental disability and emotional/behavior challenge were conducted in 2018 and were submitted to SCLARC and ELAFRC on November 26, 2018 and are included in this report pages [4 -8]. The focus groups for Priority 2) parents who are regional center consumers who have children 0-3 were conducted in 2019 and the results are detailed on pages [9 -12]. The online survey for service coordinators was conducted in 2019 and the results are detailed on pages [13 -17].

For this report, the term “parent” will be used generically to describe both birth parents and relative caregivers.

Priority 1 Parents of Children 0-3 with a Developmental Disability and Emotional/Behavior Challenge

Each entity was responsible for recruiting participants for the focus groups in their area. The focus groups were conducted on September 12, 2018 (SCLARC) and September 20, 2018 (ELAFRC). BRAID conducted two focus group to gather information regarding the needs of parents/caretakers of young children with developmental disabilities and emotional/behavior challenges. The focus groups were attended by a total 9 parents and 1 relative caregiver.

The first focus group was comprised of parents/caregivers who were consumers of South Central Los Angeles County Regional Center (SCLARC). The focus group was conducted by Fran Goldfarb, and notes were taken by Luisa Gutierrez. There were 4 parents attending representing 3 families. One of the parents was monolingual Spanish speaking and did not participate, however his wife did. One participant was a relative caregiver. All the qualifying children were 2 years old. One parent had been receiving services for less than one month. Early Start services included: OT (3), Speech (3), PT (1), ABA (1), 1-on-1 (1). Behavioral/mental health services included: ABA (1), PCIT (1), waiting to begin ABA (took behavior class) (1), waiting for approval for helmet (1)

The second focus group was comprised of parents/caregivers who were consumers of the Eastern Los Angeles Regional Center (ELARC). The focus group was conducted by Fran Goldfarb, and notes were taken by Luisa Gutierrez. There were 6 parents attending representing 5 families. One of the parents was monolingual Spanish speaking and did not participate, however his wife did. The families had a total of seven children. The ages of the children were 2, 3, 8, 15, 13, 20. There was an additional child mentioned but his age wasn't given. The parents were asked to "please think about when your child was under 3 and answer the questions based on that". All the families received Early Start Services through ELAFRC. Early start services included: Speech (3), OT (2), PT (1), Behavioral (1), Center-Based Program for Socialization (1). One child would be starting social skills (but hadn't yet). The parent of the 20-year-old couldn't recall what Early Start services were received.

Focus Group Protocol Summary

Ten questions formed the basis of each focus group discussion. Please see Appendix A for complete protocol including introduction and prompts. Sessions were recorded and transcribed. Participants provided information about the following areas:

- Previous personal experiences with Early Start including what was most and least helpful.
- Previous personal experiences with mental health services including what was most helpful, least helpful and barriers to accessing services/supports.
- The types of services/supports that would have been helpful to them
- The types of services/supports that would be helpful to other parents
- Parent groups that may have special needs
- The preferred format(s) for services/supports
- Identifying enticements for participation.
- Identifying the potential barriers to participation and recommended solutions.

- Important information for professionals working with parents of children 0-3 with developmental disabilities/delays.
- Important information for professionals working with parents of children 0-3 with developmental disabilities/delays and emotional/behavioral challenges.

Summary of Responses

Early Start –

Most helpful

Parents were asked what was most helpful about the Early Start Services they received. In general, parents endorsed services that showed results. They were particularly appreciative of services that addressed behavioral concerns (3) or developmental skills including gross motor (2), occupational therapy (2).

Least helpful

Conversely, parents reported least helpful services were those that did not produce results, in particular speech therapy (2) and behavior. One parent also shared that the service coordinator didn't help the parents understand services and didn't provide choices in service providers. This parent also felt the vendor was provided out of convenience rather than a good match for the child.

Mental Health Services –

Most helpful

Parents reported less involvement with mental health services, either through Department of Mental Health or regional center. Four (4) parents reported that they didn't receive mental health services. Two (2) are receiving ABA through generic resources (private insurance). Those that received services reported that services that addressed behavioral concerns were most helpful. Those services included: OT, Behavior Classes and calming strategies. Although few families were receiving mental health services, all families reported that mental health services were needed.

Least helpful

Parents reported delays in receiving services as the least helpful aspects of mental health services (2). Several parents were still in the evaluation stage or waiting for services to begin (3) and therefore had no comment.

Barriers to Receiving Mental Health Services

Parents reported the barriers to receiving mental health services. These barriers included sending the parent back and forth between regional center and health insurance (poor communication between systems), late diagnosis, and delay in receiving services (2).

Services that would have been helpful included recreational/social activities for families (2) and more inclusive activities (child involved in baseball not being allowed to play because of autism).

What types of support would have been helpful to you?

Parents reported that supports that would be helpful included respite (2), active support groups (4), more awareness/acceptance of developmental delays (4), better training for professionals, e.g. physicians. Respite was identified as especially important for grandparent caregivers.

What would be helpful to other parents?

When asked to identify supports/services that would be helpful to other parents; participants endorsed some of the issues identified above (services needed by them) but largely focused on how services were coordinated rather than specific services. Concerns included lack of coordination across systems/providers (2), lack of follow-through (don't call back) (2), lack of awareness in primary care providers, lack of communication with parents, delay in starting/receiving services and need to use advocacy services.

Parent groups that may have special needs?

Parents identified the following as groups that might have special needs or need services targeted to their needs: working parents, minority parents (2), families in poverty or without insurance (2).

Services/Supports BRAID Should Develop

Parents requested expansion in current services; either more programs or services on weekends. They also recommended programs similar to Big Brother/Big Sister (mentor programs) that can work with very young children and educational programs for young children (2), programs for children on Saturdays, better support services for parents during time of illness/crisis, training for parents (e.g. IEP training), educational programs for "older" relative caregivers and better training for service coordinators/better service coordinators

Frequency of Services

When asked how often services should be provided, parents suggested that services should be available every day, depending on the need of the parents (2). More specific suggested included: evenings, online programs, 1-2 times a month.

Barriers to Using Services/Supports

Barriers to using services included time (3), lack of awareness of services (2), competing needs of other children, needing to clean house before home based services, transportation and childcare.

Recommendations to Address Barriers

Parents mentioned the following as potential solutions: provide an Access card or a shuttle for transportation, fund childcare, better communication with the medical community.

Enticement to Use Services/Supports

In general, parents feel that programs would be attractive because they fulfil a need. Parents also suggested skilled childcare, programs in multiple languages and various topics (but caution to focus on only one topic at a time), improving the website so that it was easier to access information and increased outreach and use of social media.

Languages

Programs should be offered in English, Spanish (4), Korean, Chinese, Vietnamese, Tagalog and a recommendation to check the regional center demographics.

Important Things for Professionals to Understand About Working with Families of Young Children with Developmental Delays or Disabilities

Parents had numerous recommendations mostly stemming from their concerns that professionals don't understand the realities of families. Several families spoke to the lack of understanding when parents have to cancel/reschedule appointments due to scheduling conflicts or illness of the child (2). Comments included that providers have rigid re-scheduling policies ("3 strikes and you're out"), don't understand that parents may have more than one child receiving services; that they are juggling appointments and need flexibility in appointment times and that providers should help families address barriers rather than refuse services.

Parents reported that caring for their child was burdensome; sharing high levels of fatigue, lack of "me time" for parents and depending on support of family members to be able to care for their families (6). Additionally, parents had concerns about the amount of time spent in direct services. One parent was concerned that too much of the session wasn't spend directly with the child and that professionals only provide a 50-minute hour, but aren't understanding if parents are late to appointments. There was a concern that not all service providers are trained (or adequately trained). A parent suggested that regional center should do more research on their vendors.

Parents also felt professionals needed to know that many parents don't understand their child's diagnosis and/or needs and that all of this can be very distressing for parents, that parents are sympathetic to the stresses of professionals working with their child's behavior and that parents benefit from training.

Important Things for Professionals to Understand About Working with Families of Young Children with Developmental Delays or Disabilities and Emotional /Behavior Needs

Parents expressed concern that service providers may not be parents themselves and therefore may not appreciate the realities of their lives (3). It was recommended that service coordinators have the

experience of taking care of a child with emotional /behavior challenges to better understand parent concerns. Parents shared they are taking a “leap of faith” when they start working with a provider/service coordinator. How difficult it is to get to meetings and that services and meetings should be provided “in-home”. Parents should have access to a service coordinator profile on the website and parents should be asked to evaluate their service coordinator.

Priority 2 - Parents Who Are Regional Center Consumers and Who Have Children 0-3

Recruitment was difficult for this group of parents. Between 4-6 parents were recruited for each of the groups but ultimately only four (4) parents participated. One parent participated in a phone interview on 2/15/2019. The focus groups were conducted on February 21, 2019 (SCLARC) (2 parents and 1 parenting support provider (SCLARC Vendor)) and March 18, 2019 (SCLARC) (1 parent and her mother).

Due to the difficulty in both recruiting parents and getting informative responses from the parents, Fran Goldfarb met with Yvette Baptiste and Maura McGinnis Gibney and suggested gathering information from the service coordinators as well. Ultimately, it was decided to develop an online survey of service coordinators (of adult consumers).

The key informant interview took place on February 15, 2019. The KII was conducted by Fran Goldfarb, who also took notes. The parent is a regional center consumer (ELARC) did not know how long she had been a consumer but thought since her child was a baby. The child was 4 months old was just accepted as an Early Start consumer. The child is in out of home placement (DCFS). Parent services include: transportation, ILS and parenting support (hadn't started yet).

The first focus group was comprised of 2 parents who were consumers of South Central Los Angeles County Regional Center (SCLARC) and one parenting support provider. The focus group was conducted by Fran Goldfarb, and notes were taken by Luisa Gutierrez. Both parents were regional center consumers; the first from age the age of 10-11, the other reported "since she was very young. One child was 1 year old and the other child was 3months old. Neither child was a regional center consumer, although the 3-month-old was to be evaluated for services the following week. The one year old child was in out of home placement through DCFS. One parent had been receiving services for less than one month. Parent services included: independent living services (both) and parenting support (1).

The second focus group was comprised of 1 parent who was a consumer of the SCLARC and her mother. The parent spoke English, the grandmother was a mono-lingual Spanish speaker. The focus group was conducted by Fran Goldfarb, and notes were taken by Luisa Gutierrez. The parent is a regional center consumer and has received services for 15 years (mother's report, consumer reported for 2 years). The child was an infant (age not specified) and is receiving Early Start services. Parent services include: transportation (parent report), parenting (anger management) classes – source unspecified.

Focus Group Protocol Summary

Ten questions formed the basis of each focus group discussion. Please see Appendix B for complete protocol including introduction and prompts. Sessions were recorded and transcribed. Participants provided information about the following areas:

- Previous personal experience as a consumer of regional center including parenting supports
- Previous personal experiences with Early Start including what was most and least helpful.

- Previous personal experiences with mental health services including what was most helpful, least helpful and barriers to accessing services/supports.
- The types of services/supports that would have been helpful to them
- The types of services/supports that would be helpful to other parents
- Parent groups that may have special needs
- The preferred format(s) for services/supports
- Identifying enticements for participation.
- Identifying the potential barriers to participation and recommended solutions.
- Important information for professionals working with parents who are regional center consumers and have children 0-3.

Summary of Responses

It is important to note that all the parents had difficulty answering the questions and required many prompts. Therefore, there is some question as to whether this truly reflects the parents' experience and ideas. The parents also answered "I don't know" or didn't respond to many of the questions.

Regional Center Services (Parent)

Most Helpful

The general regional center services that parents found helpful included: helping to find a job, an afterschool program (needed to have child returned per DCFS), help with transportation,

Least helpful

The parents didn't identify any services that weren't helpful; one felt all services were helpful, one responded "I don't know". One parent is trying to get her child back from out of home placement and identified the regional center hadn't helped with that yet.

Parenting support

Most helpful

Two parents identified parenting classes as helpful, but were unable to state whether the classes were through regional center or DCFS. One parent responded, "I don't know".

Least helpful

One parent felt everything was helpful.

Early Start Services

Most Helpful

Only 2 of the children were Early Start participants. One was just accepted and hasn't started services yet. The other is currently receiving services but didn't identify services.

Least helpful

The parents didn't identify any services that weren't helpful.

Mental Health Services – Parent

None of the parents are currently receiving mental health services. One is going to start stating that this is the first time she felt she needed them to help her and her child. Another responded that she isn't receiving services but sometimes she thinks she needs them. One parent said that the court would like her to receive services. None of the children are receiving mental health services, however one parent thought it would be helpful for her child.

What types of support would have been helpful to you?

One parent felt that parenting classes would be helpful. It would also be helpful if regional center could "call and check before things fall" She reported that she had several DCFS referrals "Every report was a false report. Would have been helpful if DCFS knew more about parents who are regionals center consumers." Another parent asked for help learning to care for her child. She wasn't sure if the classes were in the home or not, but she would like in-home support.

What would be helpful to other parents?

One parent thought having in-home support (someone to help them out) would be helpful. Another suggested a home visitor to teach things and to provide a break.

Parent groups that may have special needs

Mothers who don't speak English or are young (please note these were the examples).

Services/Supports BRAID should develop

Although most of the parents didn't have a response. One parent suggested transportation which should be available for 2 years. Another suggested helping parents get SSI.

Frequency of services

Parents didn't have a response.

Barriers to using services/supports

Parents didn't have a response.

Recommendations to address barriers

Parents didn't have a response.

Enticement to Use Services/Supports

Parents didn't have a response.

Languages

Parents didn't have a response.

Important things for professionals to understand about working with parents who are regional center consumers.

Parents didn't have a response.

Service Coordinator Responses

An online (Google Forms) survey was developed to gather additional information regarding the needs of parents who are regional center consumers and have children 0-3. The survey was reviewed by SCLARC leadership and was opened on September 23, 2019 for SCLARC Service Coordinators on the Adult Units. It was closed on October 21, 2019. The last survey was submitted on October 1, 2019. A total of 12 surveys were collected.

Survey Protocol Summary

The survey consisted of 11 questions. Please see appendix C for complete protocol including introduction. Participants provided information about the following areas:

- Number of years as a service coordinator
- Number of consumers who were parents (in total career)
- Number of consumers who were parents (on current caseload)
- Decision tree for referring children to Early Start
- The types of services/supports received by parents (including most helpful and barriers)
- Number of parents with DCFS
- Likelihood of DCFS involvement
- Types of services/supports that would be helpful (including Parent groups that may have special needs)
- Important information for professionals working with parents who are regional center consumers and have children 0-3.
- Important information for service coordinators working with parents who are regional center consumers and have children 0-3.
- Is it helpful to know which consumers have children who are also regional center consumers.

Summary of Responses

Number of years as a service coordinator

The responses ranged from 1 year to 27 years. Five had been a coordinator for 5 or fewer years. Seven had been a service coordinator for over 10 years.

Number of consumers who are parents (in total career)

The responses ranged from 1 to 175. Nine responded fewer than 15. Three responded with more than 50 (50, 100, 175).

Number of consumers who are parents (on current caseload)

The responses ranged from 0 -50. One responded 0. Ten responded 10 or fewer and one responded 50.

Decision tree for referring children to Early Start

None of the service coordinators report routinely referring child of regional center consumers to Early Start. Three (25%) refer if the child appears to have or be at risk for a delay. Four (25%) refer if the

parent is concerned. Three (25%) report not generally referring. Two (16.7%) report not knowing how to refer a child to Early Start.

The following choices were allowed

- a. I refer all young children of regional center consumers to Early Start (0%)
- b. I refer young children of regional center consumers to Early Start if the child appears to have or be at risk of a developmental delay. (25%)
- c. I refer young children of regional center consumers to Early Start only if the parent expresses concerns. (33.3%)
- d. I refer young children of regional center consumers to Early Start if a service provider recommends it. (0%)
- e. I generally do not refer young children of regional center consumers to Early Start. (25%)
- f. I do not know how to refer to Early Start. (16.7%)

Types of Services

All the service coordinators listed Parenting Training Services as a service provided. Other services included: Supported Living Services (6) – some service coordinators referred to SLS as synonymous with parenting training services, Respite (2), IHSS (2), SSI (2), parenting class (2), parent support group (1), IEP (1), referral to DPSS (1), Work Activity Program (1), Independent Living Services (ILS) (1), Daycare assistance (1), WIC (1), Medi-Cal (1), Wrap around Me Services (1).

Most Helpful

Parenting Training Service (10), SLS (4), respite (1), legal services (1), diapers (1), support groups (1), parenting coordinator (1), Wrap around Me Services (1), FRC donations, Independent Living Services (ILS) (1), Work Activity Program (1)

Barriers to Using Services

None (SC didn't experience or observe barriers) (3), parents not need for service (due to fear, inability or not perceiving need) (3), lack of vendors (2), transportation (2), childcare (for other children) (2), inability to contact parent (1), not enough funds, SC's lack of knowledge of services and resources.

Involvement with Child Welfare

Except for one, all the SC reported that at least one of their consumers (in their career) had involvement with child welfare. The responses ranged from 0 to 15 consumers. Four (25%) SC reported they had 2 consumers with child welfare involvement. The following were reported by one SC each

- 1 consumer,
- 2 consumers.
- 3 consumers
- 4-6 consumers
- 5 consumers

- About 15 consumers
- None

Likelihood of Involvement with Child Welfare

All the services coordinators responded that there was at least some likelihood of involvement with child welfare. Three (25%) felt that involvement was very likely, five (41.7%) felt it was somewhat likely, one (8.7%) felt it was likely and three (25%) felt it was not very likely.

Recommendations to BRAID for Services

Eleven service coordinators responded to this question. All recommendations are detailed below:

- one to one parenting with children.
- parenting classes that has nothing to do with the behavior of a child.
- DCFS information
- Besides parenting support, I think support to the children as well. They may not understand what is going on and how to help
- Parents of young children need to learn how to play with their children and learn how to provide stimulation. It has been my experience, not only with parents that are RC consumers that they do not interact with their children.
- There is a lack of playtime from the parents.
- Male consumers typically have problems with visitation rights, without legal intervention they are not/have not been allowed to see/know their children.
- Another issue has been the need for childcare for parents that have wanted to have a job, that has been an ongoing issue.
- Reliable quality vendors that specialize in parenting would be advantageous, somehow the line between parenting and SLS seem to become blurry as the program design does not always match the actual services. For example, for consumers that cannot read, requests are made to help with their children's homework, but the child does not receive the requested help.
- It would be helpful for parents to have childcare / parenting services for all of their children (Regional Center and non-Regional Center). For example, when help is provided to the parent based on if their child is with the Regional Center versus helping the child because the parent is with the Regional Center the effort to provide the parent with help is often met with complaints, such as "what am I supposed to do about my other child(ren)?" This has typically been an issue when the parent has needed childcare.
- Education, Safety awareness, Family Counseling/Therapy
- support groups, connection to generic services.
- Parenting services and education on generic funded resources.
- Parenting coordinator, or some sort of transportation
- Educational support, nutrition support, counseling services
- Resources for Daycare for the consumer's that would like to work.

- parenting classes, sex education classes, more frequent visits to monitor parent and child, housing for consumer families with children

Particular parenting situations that require more or different support

Nine SCs responded to this question. One SC didn't feel there were situations that required more or different support. The responses of those that felt there were:

- DCFS (2)
- Children with behavioral issues and mental health issues
- Language is always a barrier (2)
- When both parents are consumer and seeking custody or joint custody
- Consumer with children that are also consumers (2)
- Children with medical issues.
- multiple diagnosis,
- more than one child,
- mental health

Important information for professionals working with parents who are regional center consumers and have children 0-3.

Eleven SCs responded to this question. Their responses were:

- That they do not understand many things about their children's needs
- That they may need more help but to not assume they do or that they are not capable of parenting
- This particular population is capable of parenting with appropriate support and education.
- Although the parent may present well, oftentimes the parent is not always able to process all the information that is presented when dealing with other professionals. For this reason, other professionals should be open to allowing the parent to have his/her SLS Instructor present to assist the parent with communicating and understanding the breadth of the meeting. It is often that consumers report "I did not really understand what they were telling me."
- They need more coaching on looking at the long-term outcomes rather than the immediate results.
- Be patient with the consumer
- The professional needs to understand that the parent needs to have the support to help with her child's needs - parenting skills.
- Patience
- Additional supports maybe needed.
- We see the consumers either quarterly or annually and as professionals we have to be compassionate to these parents especially if we are not parents of a disabled child. Parenting an individual with a disability can be a life time situation. As professionals, we must handle the situation with care and compassion.

- They may need support the parent may not agree to or be aware they could benefit from due to their own needs.

Information that would be helpful for SC to learn or know more about.

Ten SCs responded to this question. One SC felt this question was not applicable. Their responses of those with recommendations were:

- DCFS
- Generic supports that may be useful for the family
- Is there any Mommy and Me classes available for our population to attend to provide the guidance on how to interact with their children?
- Are there services for consumer's children that are ages 3-16 that are not with the Regional Center as well as with the Regional Center? That would be helpful. Consumers with children are family focused on themselves and the needs of their children.
- Parent training
- Connecting them to as many services as possible, regional center and generic
- More generic resources about day care to allow the parents to work or attend school without having to worry about their child's care.
- any referrals they may need (daycare, behavioral assistance, after school programs, weekend care, community outings for families with disabled children).
- A procedure put in place on how to support a parent consumer with SCLARC services/generic supports or have an assigned person that has all the information on resources/supports that an SC can go to support the parent consumer.

Lastly, the SCs were asked if it is helpful to know which consumers have children who are also regional center consumers?

All twelve (100%) SCs felt this would be helpful.

Recommendations

Recommendations for Priority 1

In general parents endorsed the following:

- Better access to information; including improving regional center website, use of social media, more information on available services
- Better communication with and to providers; including better outreach to physicians to encourage early referral, better coordination of services (providers talking to each other) and training to enhance empathic attitudes and treatment.
- Services to support the caregivers; including respite, support groups, increased availability of activities to engage children, training, better training on how to use Early Start and education, services tailored to the needs of older caregivers.
- All services should be available in English and Spanish with other languages as reflected by regional center demographics. Childcare and transportation should be provided (as needed).

Recommendations for Priority 2

Talking with parents helped identify the following:

- It is not unusual for parents to have DCFS involvement. Parents did not report understanding of why their child was in out of home placement. It is important for DCFS staff to have training specific to working with parents with developmental disabilities. It is important for parents to have developmentally appropriate explanations as to why their children are in placement and how to get them back. It is important to utilize supports available to prevent the need for out of home placements.
- Some of the parents identified the requirement of court mandated parenting classes. It is important that parents have access to classes that are developmentally appropriate and would meet the requirements of the court.
- Most of the parents didn't know what services they were receiving. Those who reported services often confused regional center services with those from other systems, e.g. court mandated parenting classes. It is important for parents to be able to identify their services and participate in the planning of their services and supports.
- There are few mental health services available to parents who have DD/ID. It is important to identify/develop sources for mental health services.

Service Coordinator Recommendations

The following recommendations are based on information provided by services coordinators

- All service coordinators need to know how to refer children to Early Start.
- Children should be more routinely referred to Early Start.
- It would be helpful to have specific procedures for working with parents who are consumers

- Training for SCs on working with regional center consumers who are parents.
- SCs need good resources for consumers who are parents.
- There is a need to identify and/or develop parenting support vendors.
- Vendors need training on working with parents who are regional center consumers.
- Service Coordinators need to know more about DCFS.
- Service Coordinators need support to develop plans that can prevent and/or lessen involvement with Child Welfare.

Appendix A

BRAID

SCLARC/ELAFRC funded by MHSA

Focus Group Questions

Group 1 – Parents of children who have a DD and behavior/behavioral health issue 0-3

Introduction:

Thank you for agreeing to participate in today’s focus group. We appreciate your help. My name is Fran Goldfarb and this with Louisa, our note taker and Gloria Ruiz, who will help with the logistics. We are working with South Central Los Angeles Regional Center and the Eastern Los Angeles Family Resource Center on a project called BRAID which will provide training to professionals on how best to help families of young children 0-3 who have a developmental delay or disability to support their child’s emotional needs. To do this, we need to hear from parents on what is important and helpful to them. This project is funded through the Department of Developmental Services Behavioral Health Services Act Cycle IV funding.

Over the next few weeks we will hold focus groups so that we can get the opinions and ideas from parents in the South Central Los Angeles and Eastern Los Angeles Regional Center areas. Before we start let’s go around the group and introduce ourselves. Please tell us:

- **Your first name**
- **The age(s) of your child(ren)**
- **Your favorite color**

Thank you. Today we are going to ask you some questions about services and supports you received when your child was under age 3. If your child is over 3, please think about when your child was under 3 and answer the questions based on that. We will use your ideas and thoughts (along with those from the other groups) to help us design our program.

Ask the group if anyone has participated in a focus group before.

If you haven’t participated in a focus group before, or even if you have, I would like to explain how this group will work. I will ask you some questions and would like your responses. There are no “right or wrong” answers to these questions. However, we ask that you respond to the question being asked (even if there is something else you would like to talk about). We are looking for a variety of responses so the group doesn’t have to agree on a single response or vote for the most popular one. For example, if I ask you what your favorite flavor of ice cream is; one person may say “pistachio”, another might say “chocolate” and a third might say “I really don’t like ice cream” – those are all helpful responses. But if you say “cats”, that answer doesn’t help us so much.

We are recording this focus group and Louisa is taking notes so that we have an accurate record of your responses. We are just using what you say, but we are not identifying who said it. You do not have to answer every question. But remember, all your ideas and opinions can help us to help others so please think about each question and give us your thoughts.

I just want to take care of a few housekeeping items.

- The bathrooms are located [fill in location]. If you need to go to the bathroom, just get up quietly.
- We have some snacks, if you need something to eat or drink, feel free to get up quietly at any time.
- Please put your cellphone on vibrate. If you get an emergency call, please step outside to take the call. We ask that you wait to respond to non-emergency calls until after the group.

Are there any questions? [Respond to any questions]. All right let's begin.

1. We would like to know about *your* experience with 0-3 services.
 - a. Did your family receive Early Start (0-3) services through regional Center?
 - If yes, please describe.
 - What did you find the most helpful about Early Start?
 - What did you find least helpful about Early Start?
 - b. If no, when did you start receiving services, and why?
2. We would like to know about your experience with emotional/behavioral health services.
 - a. Did your family receive emotional/behavioral health services for your < 3-year-old child?
 - If yes, please describe.
 - What did you find the most helpful about the emotional/behavioral health services?
 - What did you find least helpful about emotional/behavioral health services?
 - b. If no, do you think emotional/behavioral health services were needed?
 - If yes, what prevented you from receiving services
3. Think about when you your child was under 3, what types of support would have been helpful to you? (prompts: things like managing stress, help with behavior)
 - a. What types of supports do you think would be helpful to *other parents* of young children with developmental delays or disabilities
4. Can you think of any types of parents of young children that may need different or more support and information (prompt: such as children with behavioral challenges, parents who don't speak English, etc.)?
5. What type of services/supports do you think BRAID should develop?
 - a. How often do you think services should be provided?

- b. What days/times do you think services should occur?
6. What do you think could make it hard for parents to use services/supports? (prompt: transportation, childcare, time of day)
 - a. What recommendations do you have to address these barriers?
 7. What do you think would make families want to use services/supports? (prompt: a friend recommends, offered in [] language).
 8. What languages do you think we need supports/services groups in?
 9. What do you think is important for professionals to understand about working with families of young children with developmental delays or disabilities?
 10. What do you think is important for professionals to understand about needs of families of young children with developmental delays or disabilities and emotional /behavior challenges?

Appendix B

BRAID

SCLARC/ELAFRC funded by MHSA

Focus Group Questions

Group 2 – Parents who have a DD and children w/wo DD and/or behavior issues

Introduction:

Thank you for coming to today’s focus group. My name is Fran Goldfarb and this with Louisa, our note taker and Gloria, who will help with today’s focus group. We are working with South Central Los Angeles Regional Center and the Eastern Los Angeles Family Resource Center on a project called BRAID which will help families of young children 0-3 by training professionals on how to best work with them. This project is funded through the Department of Developmental Services Behavioral Health Services Act Cycle IV funding.

This meeting is a focus group. In a focus group, we ask questions to learn what parents think. This helps up design a program that is helpful to professionals and also to families. We want to hear your ideas. We are doing another focus group in the South-Central Los Angeles and Eastern Los Angeles Regional Center areas. Before we start let’s go around the group and introduce ourselves. Please tell us:

- **Your first name**
- **The age(s) of your child(ren)**
- **Your favorite color**

Thank you. Today we are going to ask you some questions about services and supports you receive and about services your child received when your child was under age 3. If your child is over 3, please think about when your child was under 3 and answer the questions based on that. We will use your ideas and thoughts (along with those from the other groups) to help us design our program.

Ask the group if anyone has participated in a focus group before.

If you haven’t participated in a focus group before, or even if you have, I would like to explain how this group will work. I will ask you some questions and would like your responses. There are no “right or wrong” answers to these questions. However, please answer the question I ask (even if there is something else you would like to talk about). For example, if I ask you what your favorite flavor of ice cream is; one person may say “pistachio”, another might say “chocolate” and a third might say “I really don’t like ice cream” – those are all helpful responses. But if you say “cats”, that answer doesn’t help us so much.

We want to hear everyone's thoughts, so please answer as many questions as you can. Also the group doesn't have to agree on the answers or vote for the most popular one. Everyone's thoughts are important. We are recording this focus group and Louisa is taking notes so that we have an we remember the responses. We are just using what you say, but we are not identifying who said it. You do not have to answer every question. But remember, all your ideas and opinions can help us so please think about each question and give us your thoughts.

Before we start, I want to let you know a few things.

- The bathrooms are located [fill in location]. If you need to go to the bathroom, just get up quietly.
- We have some snacks, if you need something to eat or drink, feel free to get up quietly at any time.
- Please put your cellphone on vibrate. If you get an emergency call, please step outside to take the call. We ask that you wait to respond to non-emergency calls until after the group.

Are there any questions? [Respond to any questions]. All right, let's begin.

1. We would like to know about your experience with Regional Center
 - a. How long have you been a consumer?
 - b. What services do you get from regional center?
 - What is helpful about regional center?
 - What isn't helpful about regional center?
 - c. How does your service coordinator help you?
 - d. Did you get any services to help you be a good parent from regional center?
 - If yes, please describe.
 - What was helpful about these services?
 - What wasn't helpful about these services?
2. We would like to know about *your* experience with services for young children 0-3.
 - a. Did your child(ren) receive Early Start (0-3) services through regional Center?
 - If yes, please describe.
 - What was helpful about Early Start?
 - What wasn't helpful about Early Start?
 - b. If no, does your child(ren) receive regional center services now (if over 3) ?
 - If yes, please describe.
 - What was helpful about these services?
 - What wasn't helpful about these services?
3. We would like to know about your experience with emotional/behavioral health services.
 - a. Do you receive emotional/behavioral health services for yourself?
 - If yes, please describe.

- What did you find helpful about the emotional/behavioral health services?
 - What didn't you helpful about emotional/behavioral health services?
- b. If no, do you think emotional/behavioral health services were needed?
 - i. If yes, why didn't you get services?
 - c. Did your family receive emotional/behavioral health services for your < 3-year-old child?
 - If yes, please describe.
 - What did you find helpful about the emotional/behavioral health services?
 - What didn't you helpful about emotional/behavioral health services?
 - d. If no, do you think emotional/behavioral health services were needed?
 - If yes, why didn't you get services?
4. Think about when you your child was under 3, what types of support would have been helpful to you? (prompts: things like learning how to care for the baby, help with behavior)
 - a. What types of supports do you think would be helpful to *other parents* with developmental disabilities?
 5. Can you think of any types of parents of young children who need more or different support and information (prompt: such as children with behavioral challenges, parents who don't speak English, etc.)?
 6. What type of services/supports do you think BRAID should develop?
 - a. How often do you think services should be provided?
 - b. What days/times do you think services should occur?
 7. What do you think could make it hard for parents to use services/supports? (prompt: transportation, childcare, time of day)
 - a. What do you think BRAID can do to help with these?
 8. What do you think would make families want to use services/supports? (prompt: a friend recommends, offered in [] language).
 9. What languages do you think we need supports/services groups in?
 10. What do you think is important for professionals to understand about working with parents with developmental disabilities?

Appendix C

SCLARC MHSA Project BRAID

Survey for Service Coordinators

Introduction:

SCLARC has received funding under the Department of Developmental Services Mental Health Services Act Cycle IV funding to identify and develop programs and training to help professionals work more effectively with families of young children 0-5, and to identify possible interventions for Regional Center Consumers who are parents.

For this survey, we are interested in the needs for regional center consumers who are parents of young children (0-3). We have talked to some parents but are also interested in the thoughts of Service Coordinators. This helps us to design programs that are helpful to professionals and to families. We want to hear your ideas.

This short survey will ask you some questions about services and supports parents and young children receive and what they may need. We will use your ideas and thoughts to help us design our program. Your answers are confidential and will be combined with those of other service coordinators from SCLARC and Eastern Los Angeles Regional Center (ELARC). This survey is being used for program design only and the results will not be published. However, we do have a drawing for a \$25 Starbucks gift card for individuals who participated in the survey. If you are interested in participating in the drawing please provide your name and email at the end of the survey.

This survey asks multiple choice and short answer questions. Please answer as many questions as you can.

1. How long have you been a Service Coordinator?
2. Approximately how many Regional Center consumers who are parents have you had in your career (as a Service Coordinator)?
3. How many individuals who are parents do you have on your caseload now?
4. Do you make referrals to Early Start for children of regional center consumers?
 - a. I refer all young children of regional center consumers to Early Start
 - b. I refer young children of regional center consumers to Early Start if the child appears to have or be at risk of a developmental delay.
 - c. I refer young children of regional center consumers to Early Start only if the parent expresses concerns.
 - d. I refer young children of regional center consumers to Early Start if a service provider recommends it.
 - e. I generally do not refer young children of regional center consumers to Early Start. (25%)
 - f. I do not know how to refer to Early Start.

We would like to know more about the services consumer parents receive:

5. What services do adult consumers who are parents of young children generally receive (please include services to help them with parenting skills)?
 - a. Which services do you think are most helpful to these parents of young children?
 - b. What, if any, barriers do they have to receiving services
6. How many of the individuals you have ever had on your caseload, who are parents, have ever been involved with Child Welfare (DCFS)?
7. In your experience, how likely is it that an adult consumer who is parenting a young child will be involved with Child Welfare (DCFS)?
 - a. Very likely
 - b. Likely
 - c. Not very likely
 - d. Not at all likely

We would like to know about services you think would be helpful to your consumers

8. What types of support would be helpful to regional center consumers who are parents to young children?
 - a. Can you think of any particular parental situation that needs more or different support and information (e.g. children with behavioral challenges, parents who don't speak English, etc.)?
9. What do you think is important for professionals to understand about working with parents with developmental disabilities?
10. What information would be helpful for you to learn or know more about to help you better serve adult consumers who are parents?
11. Would it be helpful for you to know if your adult consumer's children were also regional center consumers?