## Korean Parent Support Group meeting on February 3rd, 2016

## **Minutes**

Number of participants: 15 parents

Where: Good Shepherd Presbyterian Church in Rowland Heights.

 This meeting was scheduled during the Korean Parent Support Group regularly scheduled meeting at Good Shepherd Presbyterian Church.

Translation: SG/PRC Service Coordinator was present to provide translation and technical support.

Meeting Summary: Meeting started at 4:30 p.m. Nancy Bargmann, SG/PRC Associate Executive Director, was introduced as the person who would be presenting the data. Other members of SG/PRC staff present were Lucina Galarza, Director of Client Services; Carol Tomblin, Director of Information and Compliance; Edith Aburto, Manager of Client Services; and, Amos Byun, Service Coordinator who speaks Korean and has a number of Korean clients assigned to his caseload.

A power point presentation was used to guide the audience through the data and related charts, update from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for ease of reference. The majority of the members of the audience spoke and understood English. Mr. Byun opened the meeting in Korean and provided translation to the one or two people who wanted to hear the presentation in Korean.

Ms. Bargmann reviewed the information on each of the slides and encouraged discussion if there were any questions or comments. Following the 30 minute presentation, there was an open discussion about what was presented and to encourage input in terms of what SG/PRC could do differently to help make the authorizations and utilization more equitable. Specifically, what did they see as any current or potential barriers and ideas to remedy these areas.

One person wanted to understand better why whites tended to have a higher percentage of their family members placed in residential care, as Korean families believe that the families should stay together. The parents remarked that Korean families typically do not prefer for their children to live in facilities -- this was in response to the data representing that the white population reflected a greater percentage living in residential facilities.

One comment was regarding a situation that occurred about three years ago, but this type of issue may still be relevant:

Parent had a respite provider who did not have enough information about dealing with a child with autism and behavior challenges ("regular" respite provider). Parent did not know that SG/PRC has some specialized respite providers who have more training and supervision by those who have behavior training. Rather than ask for a different provider or tell her SC that this was

not working for her, she "gave up" on respite and has not had respite services for several years now.

One parent shared an individual situation experienced many years ago when SG/PRC paid parents directly for respite services (over 5 years ago), she would get too busy to file the report of the hours worked – exceeding the 90 day period. Therefore, she would not get paid for the services that were performed. This exact situation does not exist now, but the group that there may be some issues with parents verifying the work performed in a timely manner that might mean that some respite workers were not paid for all hours.

When asked what they thought might get in the way of using authorized services, another parent said she did not understand the regional center system well enough and did not know what to ask for. It appears this may be related to authorization rather than utilization supporting the concern that families may not be receiving information in the person's native language. The group expressed that it was important to them, even if they spoke English, that having an SC that speaks the persons preferred language would be a benefit to the coordination of services. Additionally, a parent indicated that not having enough materials in own language was problematic.

Independent Living Services (ILS) became an important topic for the group as an alternative to out of home residential service models. Most parents in the meeting were not aware that they could request ILS training for their adult child living in their home. It was concluded that being informed about services and changes in statute regarding services was crucial and important to communicate to the community.

Lastly, a parent expressed concern regarding the opportunity to explore tailor day program for her son who needs some type of activity during the day. Parent reported that her son, a 24 yrs old male (UCI# 1978037) does work in the evenings and that a second part time job might be appropriate for him. Staff from SG/PRC will have the service coordinator work with the family regarding his plan. Secondly, she was specific in wanting to have a Korean speaking SC. Edith Aburto, Program Manager shared this information with the SC and Manager for individual follow up.

The formal meeting was concluded about 5:30 p.m., but those who were interested and able were invited to stay and talk more informally. The meeting was concluded at approximately 6:00 p.m.

# Filipino Parent Support Group meeting on February 13th, 2016

#### **Minutes**

Number of participants: 21 parents and family members

Where: San Gabriel/Pomona Regional Center (SG/PRC)

• This disparity data meeting was scheduled as a part of the Filipino Parent Support Group that is regularly scheduled to meet at SG/PRC.

Translation: No translation was needed. All participants were English-speaking.

Meeting Summary: Meeting started at 9:30 a.m. First part of the meeting was for a different presenter regarding IEP and parents' educational rights. The Disparity Data portion of the meeting began a little after 10:30 a.m. Carol Tomblin, SG/PRC Director of Information and Compliance was introduced as the person who would be presenting the data. Other members of SG/PRC staff present were Lucina Galarza, Director of Client Services and Ro-Anne Balino, Service Coordinator who supports several of our clients who are Filipino and assigned to her caseload. Three members of the audience were also staff of SG/PRC.

A power point presentation was used to guide the audience through the data and related charts, update from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for ease of reference.

Ms. Tomblin reviewed the information on each of the slides and encouraged discussion, questions and/or comments. Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (utilization of authorized services) was explained. Part of the presentation pointed out the disparity of the percentage of Filipino families that have no Purchase of Services from the regional center compared with other ethnic groups.

The agenda encouraged community discussion during the meeting and further input at the conclusion of the meeting. There was a question as to whether we collect data by ethnicity; and if so, which geographic areas these data covered. There was also a question as to the representation of the clients of regional center in comparison to the ethnic composition of the communities we serve. There was a brief discussion about needing to look at the Census Bureau data following the next census to compare with the people who show up at the Regional Center for services.

There was also a question about clarifying the total dollar amount of authorized services versus total expenditures. The participant wanted to know if we are on a "use it or lose it" system and commented

that if so, it is important for Filipino families to use the services that are authorized "so can get the most and not have to return monies to the state." Regional Center responded by emphasizing the importance of meeting the needs of individual clients.

There was a question as why one slide made reference to Asian and another made reference to Filipino. There was also a question as to whether Filipinos were considered Asian, Hispanic or Other. The questions led to a conversation that it is important for the race to be specific so that we can meet the language and cultural needs of our community -- especially as it relates to our board and staff composition.

Following the 45 minute presentation, there was an open discussion about what was presented and to encourage input in terms of what SG/PRC could do differently to help make the authorizations and utilization more equitable. Specifically, family members were asked what they see as any current or potential barriers and ideas to remedy these areas.

The main theme of the comments from families was that Filipino families have strong commitment to their family member with disabilities. It was shared that parents of children with disabilities are find it hard to let go of their child or to trust anyone else with the care of their child/adult child. Some resources they could use to benefit them and their family members have been discussed with them, but the families have not wanted to utilize these resources as the persons providing the service were either not Filipino or even if Filipino were not family members. One person indicated that she did not even trust her other adult children to care for her disabled adult daughter because no one could care for her as she does.

Another person also emphasized that the Filipino culture emphasizes strong family ties that lead to families wanting to maintain their child in the home of the biological family or other close family members.

A primary focus of the discussion was about a parent looking toward the end of their life and the potential of out-of-home placement when the caregiver parent was no longer able to care for the adult/child. Ms. Galarza discussed the option of Adult Family Home Agency (AFHA) certified homes as well as the fact that many licensed residential facilities are owned and operated by Filipino providers. Many were not aware of the small family home setting know as certified AFHA homes that may appeal to others who otherwise would not considering placement.

The same sentiment of not trusting others to provide care seemed to be extended to respite or other services, as well.

As part of the presentation, SG/PRC shared the changes in procedures in response to previous feedback from families. Included was the development of a fact sheet with services that are available by age group. Those fact sheets are being translated and will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future. As a part of this discussion it became evident that many parents were not aware of certain services, such as 21-day out-of-home

respite or the option to utilize Independent Living services for clients still living in the family home to assist them to become more independent within the family living arrangement. Families were encouraged to use their Service Coordinators to receive service option information and support in making difficult decisions for their family members. Families were also encouraged to ask for a Filipino Service Coordinator, if they felt that was important to them and would help them access services.

Participants were encouraged to contact Ms. Tomblin, the group's facilitator or their SC to provide more of their ideas on how SG/PRC should address disparity, if those ideas came to them after the meeting. The formal meeting was concluded about 12:00 noon, but a few stayed to talk more informally.

## General Public Open Meeting on February 24th, 2016

#### **Minutes**

Number of participants: Three (3) parents and the Clients' Rights Advocate from the local office of Disability Rights California – total of four

Where: San Gabriel/Pomona Regional Center (SG/PRC)

Translation: A SG/PRC staff person was present to provide simultaneous translation into Spanish using headsets. Handouts and Power Point presentation translated into Spanish were available. No one requiring Spanish translation attended.

Meeting Summary: Meeting started at 4:30 p.m. Carol Tomblin, Director of Information and Compliance introduced herself as the person who would present the data. Other members of SG/PRC staff present were R. Keith Penman, Executive Director, Lucina Galarza, Director of Client Services, and Edith Aburto, Manager of Client Services, who was also present to provide Spanish language translation.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for ease of reference.

Ms. Tomblin reviewed the information on each of the slides and encouraged discussion, questions and/or comments. Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. Part of the presentation pointed out that there are disparities noted between ethnicity groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic groups having the highest percentage of no POS expenditures compared with other ethnic groups.

At the conclusion of the power point presentation, Ms. Tomblin encouraged input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers or ideas to remedy these areas. Although the audience was encouraged to share their ideas, comments or questions, the audience did not provide comments.

In hopes to generate discussion, SG/PRC shared the changes in procedures in response to previous feedback from families. Included was the development of a fact sheet with services that are available by age group. Those fact sheets are being translated into several languages at this time. Once completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future. The audience was told that beginning March 1<sup>st</sup>, SCs and their managers will be receiving copies of clients' authorizations and utilization each subsequent quarter, so that SCs can confer with families if the SC notes that the utilization is less than expected.

The families present seemed to appreciate the information. At least one parent indicated that she might attend the meeting scheduled on March 12<sup>th</sup> with the Chinese Parent Support group, as Mandarin is her primary language.

One member of the audience is a member of the SG/PRC Board of Directors, and he was encouraged to contact SG/PRC with any ideas that might come to mind following this meeting.

The meeting concluded at 5:30 p.m.

# Client Services Committee Meeting on February 24th, 2016

#### **Minutes**

Number of participants: 14 people, including the Clients' Rights Advocate from the local office of Disability Rights California. The audience included clients, parents, and community members who were members of the Client Services Committee. The audience also included those who support the client committee members (e.g., parent, paid staff), and one person from the general public, who is both a parent and a vendor.

Where: San Gabriel/Pomona Regional Center (SG/PRC)

Translation: Not needed.

Meeting Summary: The meeting was called to order at 6:00 p.m. by the chair of the committee. The meeting followed the standard meeting format. Following a discussion of the committee members regarding the previous month's presentation, Mr. Keith Penman, Executive Director, introduced Carol Tomblin, Director of Information and Compliance, as the special topic presenter at 6:15 p.m. Another member of SG/PRC staff present was Lucina Galarza, Director of Client Services.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for ease of reference.

Ms. Tomblin reviewed the information on each of the slides and encouraged discussion, questions and/or comments. Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. Part of the presentation pointed out that there are disparities noted between ethnicity groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic groups having the highest percentage of no POS expenditures compared with other ethnic groups.

At the conclusion of the power point presentation, Ms. Tomblin encouraged input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers to clients receiving authorized services or utilizing services, as well as any ideas to remedy these barriers.

SG/PRC also shared changes in procedures that are being implemented in response to previous feedback from families. It was presented that SG/PRC has developed a one-page fact sheet, or POS summary, indicating services that are available by age group was presented. This information is currently being translated into several languages. The audience seemed pleased that this POS information would be made more readily available and in multiple languages. The audience was told that once all of the translations are completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future.

The audience was told about another change that would begin March 1<sup>st</sup>. SCs and their managers will receive reports of clients' authorizations and utilization each quarter so that SCs can confer with families if the SCs observe that the clients'/families' utilization is less than expected.

A client who is a member of the Hispanic community indicated that he felt that many Hispanic families don't really know or understand the services that regional center can offer. He felt that SG/PRC needed to make more information available. He pointed out that some Hispanic families have limited skills in reading written Spanish, and that we might need to provide audio or video information that could be accessed from a personal cell phone as a way to help communicate the services available and how to access them.

Many of the comments seemed to focus on the difficulty in getting connected with the regional center to become eligible for services, rather than about disparity in POS for clients who were already a part of the regional center system. Specifically, there was a question as to the responsibility of school personnel to inform families of regional center and to help them get connected to regional center. The person wanted to know what the regional center was doing to reach out to the schools to do a better job of referring potential clients to the regional center. Comments included that parents felt lost and did not get any information from their schools. There was also a question about what our regional center was doing to inform physicians, pediatricians in particular, about the indicators for developmental delay and how to refer to the regional center.

In general, many comments were about outreach efforts that seem to be needed to inform the community at large. It was suggested that we participate in street fairs and various city functions, like city council meetings and other community center functions, to tell people about regional center services.

Some families shared that they went a long time before finding out about regional center. They wanted to know what we could do better so that other families would not have to go through the same thing of struggling before finding out about regional center, to be delayed in obtaining the services they needed.

Before the meeting concluded, the Client Services Committee members were reminded that SG/PRC was interested in hearing more from them, if other thoughts came to mind after the meeting. Lucina Galarza staffs the committee and can be the contact person for the members to provide more feedback.

The meeting concluded at approximately 7:05 p.m.

## **REACH Support Group Meeting on March 3rd, 2016**

#### Minutes

Number of participants: people, including the Clients' Rights Advocate from the local office of Disability Rights California and the Executive Director of The Parent's Place Family Resource Center. The audience primarily consisted of parents and family members of SG/PRC clients.

Where: The Parents' Place, 1500 S. Hyacinth Ave., West Covina, CA 91791

 This disparity presentation was scheduled as part of the regularly scheduled meeting of the REACH Support Group.

Translation: The meeting was conducted in English. All persons present spoke English.

Meeting Summary: The meeting was called to order at approximately 7:00 p.m. A member of The Parent's Place introduced, Carol Tomblin, Director of Information and Compliance, as the presenter. Other members of SG/PRC staff present were Mr. R. Keith Penman, Executive Director and Tricia Vannucci, Associate Director of Adult and Residential Services.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for ease of reference.

Ms. Tomblin reviewed the information on each of the slides and encouraged discussion, questions and/or comments. Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. Part of the presentation pointed out that there are disparities noted between ethnicity groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic groups having the highest percentage of no POS expenditures compared with other ethnic groups.

At the conclusion of the power point presentation, Ms. Tomblin encouraged input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers to clients receiving authorized services or utilizing services, as well as any ideas to remedy these barriers.

SG/PRC also shared changes in procedures that are being implemented in response to previous feedback from families. It was presented that SG/PRC has developed a one-page fact sheet, or POS summary, indicating services that are available by age group was presented. This information is currently being translated into several languages. The audience was told that once all of the translations are completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future.

The audience was told about another change that would begin March 1<sup>st</sup>. SCs and their managers will receive reports of clients' authorizations and utilization each quarter so that SCs can confer with families if the SCs observe that the clients'/families' utilization is less than expected.

The meeting concluded at approximately 8:30 p.m.

# Nuevo Dia Grupo de Apoyo Support Group Meeting on March 9th, 2016

#### **Minutes**

Number of participants: 12 people, including the Clients' Rights Advocate from the local office of Disability Rights California. The audience primarily consisted of parents and family members of SG/PRC clients.

Where: The Parents' Place, 1500 S. Hyacinth Ave., West Covina, CA 91791, the regular meeting place and time of the Nuevo Dia Grupo de Apoyo parent support group.

Translation: The meeting was conducted in Spanish. The presentation was made by Lupe Magallanes-Angel, Associate Director of Early Intervention Services at SG/PRC. The power point slides of the disparity data were in Spanish and the printed handouts of the disparity data were also in Spanish. Printouts of the English version of the power point presentation were made available, if anyone wanted a copy.

Meeting Summary: The meeting was called to order a little after 10:00 a.m. Ms. Magallanes introduced other staff members of SG/PRC who were in attendance: R. Keith Penman, Executive Director, Carol Tomblin, Director of Information and Compliance, and Sal Gonzalez, Manager of Family Services 2, who was present to assist with the Spanish translation and answering questions in Spanish.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for ease of reference.

Ms. Magallanes reviewed the information on each of the slides and responded to any discussion, questions and/or comments that were prompted by the information on the slide. Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. Part of the presentation pointed out that there are disparities noted between ethnic groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic groups having the highest percentage of no POS expenditures compared with other ethnic groups.

At the conclusion of the power point presentation, Ms. Magallanes encouraged input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers to clients receiving authorized services or utilizing services, as well as any ideas to remedy these barriers.

SG/PRC also shared changes in procedures that are being implemented in response to previous feedback from families. It was presented that SG/PRC has developed a one-page fact sheet, or POS summary,

indicating services that are available by age group. This information is currently being translated into several languages, including Spanish. The audience was told that once all of the translations are completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future.

The audience was told about another change that would begin March 1<sup>st</sup>. SCs and their managers will receive reports of clients' authorizations and utilization each quarter so that SCs can confer with families if the SCs observe that the clients'/families' utilization is less than expected.

The following comments and questions were made by the parents during the course of the meeting:

Will the information that comes out of the disparity meetings that are taking place in March be updated to the SG/PRC website?

Are services lost if they are not used?

Do respite hours have to be a maximum of 30 hours per month? In response to this, it was explained that the law provides for 90 hours in a three month period without it being an exception or exemption. SG/PRC is now offering to change the IPP to reflect that parents can have respite authorized in three-month blocks to provide more flexibility for the families.

Are respite services going to be transferred to Medi-Cal like some other services? Families were told that the regional center would continue to pay for respite services.

One person questioned if the reason Hispanic expenditures aren't as high as other ethnicities is because Hispanic families don't use residential services as much as others. Later, there was a slide that showed that exact situation, that the utilization of residential services is very low in the Hispanic group.

One of the slides pointed out that in the Early Start program, only 69% of the authorized services were used, that it was the lowest utilization of the age groups across all ethnicities. The question was if we knew the percentage of those who are not utilizing the early start services are Latino. At this point SG/PRC did not know that answer but Ms. Tomblin said that we would try to figure out the answer to that question.

One person noted that the labels on one of the slide were incorrect. Ms. Magallanes had also pointed out that the particular slide had some labels that needed to be shifted one column over — and that we would make that correction for future presentations.

There were some client-specific questions asked: How do I get more respite hours? Another person said that her son was authorized 42 hours of ABA services but in January 2016, he received only 12 hours of service. The parent asked what she should do. SG/PRC staff asked if the parent had told the service coordinator that this had happened, and the parent said "no". The parent was advised to provide this information to the service coordinator so this situation could be rectified.

One parent inquired about placement options for teenagers severely affected by Autism. This parent had visited two options given to her for placement of her 13 year old son, but she declined due to the distance between the facilities and her home. SG/PRC staff did acknowledge that there is a lack of facilities for teens that have behavioral challenges.

Following these questions and comments, Mr. Penman thanked everyone for coming and then told the parents how important it was to have been representation of Hispanic families on our Board of Directors. Parents were told that they did not need to know English to participate, that SG/PRC would provide a translator. One of the persons in the audience asked if they had to have a son or daughter with the SG/PRC to be on the Board or the Board Committees. Mr. Penman explained that there are people on the Board who live and/or work in our SG/PRC area, but they do not have family members who are clients of SG/PRC.

One person wanted to know if they would get more respite or more of other services if they volunteered to serve on the Board. The answer was that if more respite was needed so that the person could participate on the Board, SG/PRC would take that circumstance into consideration, as we discourage families from bringing their children to the Board meetings or Committee meetings.

The meeting concluded at approximately 11:40 a.m.

## Chinese Parents Association for the Disabled (CPAD) Support Group Meeting on March 12th, 2016

## Minutes

Number of participants: 15 people, including the Clients' Rights Advocate from the local office of Disability Rights California, Aimee Delgado, and Dr. Barbara Wheeler from Cal State University, Los Angeles, who helps support the Asian Youth Center and provides training to parents. The audience primarily consisted of parents of SG/PRC clients. Three adult clients were also in the audience.

Where: The Asian Youth Center, located at 100 Clary Ave., San Gabriel, CA 91776

 This meeting was held at this support group's regularly scheduled location, and during its regularly scheduled day and time of meetings.

Translation: The meeting was conducted in English and Mandarin Chinese. The presentation was made in English by Carol Tomblin, Director of Information and Compliance, and the translation for each portion of the slide was immediately translated into Mandarin by Tiffany Loong, SG/PRC Service Coordinator. Ms. Loong is fluent in both Mandarin and Cantonese; she was available to respond to questions or comments in either language. The power point slides of the disparity data were presented in English and the printed handouts of the disparity data were also in English.

Meeting Summary: The meeting was called to order a little after 10:00 a.m. Ms. Tomblin introduced herself and the other staff members of SG/PRC who were in attendance: Lucina Galarza, Director of Client Services, Beth Lin, Service Coordinator who speaks and reads Chinese, and Tiffany Loong, who provided all of the translation of the disparity data.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for reference.

Ms. Tomblin and Ms. Loong reviewed the information on each of the slides and responded to any discussion, questions and/or comments from the audience that was prompted by the information on the slide. If a question or a comment was made in English, the question/comment would be translated into Mandarin first. Then the answer or response would be given in English, followed by the translation in Mandarin. Likewise, if the question was asked in Mandarin, the question was first translated into English before being answered. This format was followed throughout the meeting so that all conversations were conveyed in both English and Mandarin. It was noted that some private conversations between parents was in Cantonese, but no one asked questions or made comments in Cantonese, so those did not need to be translated into Mandarin.

Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. The differences between

Community Care Facilities (CCF) and Intermediate Care Facilities (ICF) were briefly explained, as were Independent Living (ILS) and Supported Living (SLS) services.

Part of the presentation pointed out that there are disparities noted between ethnic groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic groups having the highest percentage of no POS expenditures compared with other ethnic groups.

The audience was encouraged to provide input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers to clients receiving authorized services or utilizing services, as well as any ideas to remedy these barriers.

SG/PRC also shared changes in procedures that are being implemented in response to previous feedback from families. It was presented that SG/PRC has developed a one-page fact sheet, or POS summary, indicating services that are available by age group. This information is currently being translated into several languages, including Chinese. The audience was told that once all of the translations are completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future.

The audience was told about another change that would begin March 1<sup>st</sup>. SCs and their managers will receive reports of clients' authorizations and utilization each quarter so that SCs can confer with families if the SCs observe that the clients'/families' utilization is less than expected.

It was also pointed out that Independent Living Services training is now offered to adult clients living in the parent home, even if they are not intending to move out into their own apartment, so that they can be more independent while still living with their parents. This is a change in the law since the Lanterman Act was changed the last year or so.

Comments and suggestions that were made during the presentation included the following:

SG/PRC should have more parent events near the Arcadia area and during day time when the kids are at school so that parents are more available to attend. Currently most of the community meeting or events are in Pomona area (at the SG/PRC offices) and during after school hours, when parents prefer to stay home with their kids. In a more general comment, there was a request that trainings be offered or events be scheduled during the day when the clients are at school or day program.

One parent said she can only speak in Chinese. When she requests a services and her Chinese-speaking Service Coordinator (SC) tells her "no", she does not know what to do next. Also, she feels that challenging her SC is being disrespectful. She feels that a parent support group is helpful because she can learn from other parents.

SG/PRC should obtain the disparity data from ELARC in order to compare with the SG/PRC expenditures. Some parents indicated that when they lived in the ELARC area, they found it easier to get services through ELARC than from SG/PRC, since they moved to the SG/PRC area.

SG/PRC should improve its website to have information available in Chinese – to have a Chinese web page and a "link" in Chinese/Mandarin resources, as well. It was suggested that there should be a way for parents to send suggestions to the regional center through the website and that the regional center can send an email response back.

Some parents believed it would be best to have the Chinese web page in both Traditional and Simplified Chinese. The request for both Traditional and Simplified written Chinese would also apply to other materials, not just the website.

There was a request to develop a "forum" on the website, which will make it easier for parents to participate in conversations and to provide feedback.

One parent indicated that most of her requests for services have been denied. She wanted to know her rights. Some parent indicated that they did not understand why a service was denied. The appeal process was explained during this meeting, but it was also noted that the materials sent out to parents about the appeal process are in English.

Parents indicated that they were not aware of all of the services that might be available for their family member.

One parent said her son was going to day program, but the transportation company called her to say that they could not pick up her son the next day. She felt it's unfair and helpless in her situation that the transportation company gave such short notice and did not have other option for her. Her son's service was authorized but could not be delivered because of the transportation issue. Plus, she could not communicate with the transportation company due to her language barrier.

One parent asked a question about why clients who live in CCF are "entitled" (that's his word) to much more monetary expenditures than the clients who live at home. It was explained that regional center has to pay the living cost and the 24-hours care, that most of the expense is associated with staff providing supervision and training.

One parent indicated that the appeal paperwork is in English, and it's too hard for him to understand and fill out. SG/PRC agreed that we would look into translating the documents associated with a denial and appealing the regional center decision.

Concerns about some Asian SCs were raised and discussed. It was explained that one reason that some parents are experiencing difficulties may be because most the Asian SC are newly hired by SG/PRC (especially in comparison to ELARC) and they are new to the regional center system. Trainings are being provided to the SCs, and they are also supposed to utilize the expertise of their managers and various committees in selecting and arranging for services. Some parents said that if there English is good enough, they have requested or prefer a Hispanic SC, as they felt that they were more knowledgeable, were able to "work around" the system better, and got more services for them than their Chinese-speaking SC.

Another parent said that the regional center should not assume that just because they are Chinese or have a Chinese name that they should automatically have a Chinese SC. The parent said that they can very easily communicate in English and prefer to have an English-speaking SC assigned to them.

A suggestion was made by one of the parents that SG/PRC may want to provide a training using a parent panel so that SCs would have a better idea of how their communication is received by parents — to gain the parents' perspective. This comment was associated with a question that one parent asked, which was if the regional center records the conversations between the SCs and the families. That parent related that he felt that some SCs speak to parents in a disrespectful manner. Several parents noted that there are not enough vendors/providers who speak Mandarin and Cantonese. That there is a delay in getting needed services because of the language barrier, and that if a Chinese-speaking provider leaves then there is a gap in service before another person is found to provide the direct service.

Also, it was noted that some of the services that are site-based are not close enough to the family home and the family can't get to the resource that is being offered to the family.

One parent asked about setting up a Trust for her adult son. She's afraid that when she passes, someone will take away her son to be placed in a licensed residential facility. It was explained that residential placement is voluntary and that the regional center does not "take away" clients as might be the case with Child Protective Services. It is the client's and parent's choice to look into placement options as a pre-arrangement or in response to the need for placement. The parent was told that regional center will continue to be involved in the client's life even after both parents are gone and there is no conservator. The regional center, through the SC, is there to help the client to make this important decision, as well as to help the parents better understand the living options available.

At this point, the regional center staff talked about options for adults, such as supported living, living in a certified home of an Adult Family Home Agency, or licensed residential care in community care facilities or intermediate care (Intermittent nursing) facilities. The option of out-of-home respite was discussed if the parent were incapacitated or unavailable for an extended period of time.

One parent indicated that her IPP translation was not good enough to understand, although it was translated into Chinese. She also felt her SC did not explain clearly about the POS policy. She did not understand that one service authorization approval (teaching personal assistant) was subject to some unreasonable conditions, to which she was not aware and nor agreed.

In general, it appeared that most of the frustration from parents was a result of their limited English skills. When their SC denies the service, the parents could not (or did not know) to go to next level. Parents conveyed that they felt stuck and had no other choice but accept the denial. They felt that they had not received much support or that advocacy had not been done on their behalf. Sometimes parents feel stuck because the Chinese speaking SC is the only person in the system they can speak to, and that is the person who has denied the service.

There was a question about if they could appeal directly to the Office of Administrative Hearings (OAH) in Sacramento or if they had to go through a lot of local steps first. It was explained that in the past there was an expectation that clients/families would start with informal hearings and then go to formal hearing if things were not resolved at the more local level. However, now, clients/families can go directly to the formal or OAH level of hearings to appeal their case.

Most of the parents in attendance at this meeting attend ELARC workshop or meetings to get information and support. But at the same time, they find out the differences between two regional centers which make them more frustrated.

The Clients Rights Advocate (CRA) was introduced to the parent. She passed out her brochure and contact information. She indicated that while she spoke Spanish, there was a CRA assigned to ELARC located in the same office. That person would be available to help with Chinese parent issues in the SG/PRC area. However, one parent said it's still difficult for him to reach out to the SG/PRC CRA because she needs a Chinese translator to talk to him anyway.

At the conclusion of the power point presentation and the general discussion, two parents stood to present formal testimony for SG/PRC's consideration. One of the parents also provided testimony for a third parent who was not able to be present. The copies of the testimony, one in English and two in Chinese, were provided to Ms. Tomblin so that they could be translated (if needed) and included in the minutes and for further consideration. Copies of the testimony are attached (along with one translation) as part of the minutes of the meeting.

The meeting concluded at about 12:10 p.m. Until about 12:30 p.m., Ms. Galarza, Ms. Loong, Ms. Lin and Ms. Tomblin all spoke with individual parents who had a variety of questions, some specific to their child's situation others general, such as the purpose for the Medicaid Waiver Signature Page.

had prepared to testify tomorrow at SGPRC's POS mtg, but something urgent came up and she can't attend

Can you help read out her testimony for her? Below is her testimony:

消費者。當我們收到服務合同的詳細資料無中文翻譯、對我們華人是很困難去理解和吃虧。有時的 ,他屬於San Gabriel Pomona Regional Center 的 文件有中文翻譯、但是城中文是不容易理解和明白。 表形式に分子 > 宏建设计里

人幫助老師請得太快跟不上。在PCC 1:photos copy technology課堂時,有個助教在他身邊輔導,幫助,鼓勵和支持他,讓他成功完成老師給他的作業。他很開心得到這一分完成的文憑。後來他想繼 道原来簽了的服務合約有付帶條件,那輔<del>助</del>助教 (teaching personal assistant) 的批准條件喺「當所 修的課堂上要用危險的工具才能有助教」。由於我簽服務合約無中文<del>室鄰</del>翻譯,雖然你們的服務 以上大學有個人幫助他。所以雖然有一條附帶條文不明们因我的英文理解能力有限,所以我就把 纖學習basic graphic, 由於這一科學用危險的工具,所以SGPRC選批准有助教輔助Andy. 這時才知 man and 中學後,任前兩年上.PCC Community Education Center。他的體氣很容易暴躁,他需要 服務合約簽了。現在雖然校方都要求有個人助教輔導Andy 上课,但我的申請都被否決了,孩子 人员有在電話中快快的解釋過,但由於當時在上班,而且我的心情很高與聽到你們批准Andy可 在PCC 上學都得不到你們的幫助和支持服務。

們的孩子完成他的需要。而且我們的文化是不習慣問很多問題,因為這對專業/政府機關專人會看 > 伬們希皇你們可以明白, 我們中國人的文化會依賴和信任你們乃專業人員, 你們是會來幫助我

一起幫助孩子們學習及成長的更 > 我們很希望你們能夠熱心幫助我們瞭解明白文件的內容。希望你們可以把服務合約,文件及給 我們的通知翻譯成中文, 並且是好價格的翻譯讓我們可以明白,

wants to personally thank you for presenting on behalf of her and Chinese families.

## Testimony from E.L.

My name is E. L. My son's name is A. L. He is a client of San Gabriel Pomona Regional Center. We receive no Chinese translation on the service contract details, which it is very difficult to understand as a Chinese and it's a disadvantage to us.

After A.L. left high school, he attended PCC for two years. He is easily irritated and needs helps from others. He can't catch up with the professor's fast pace in the class. When he took Photo Copy Technology class at PCC, there was an assistant next to him to assist him, help him, encourage and support him. Therefore he was able to complete the homework the professor gave him. He was very happy that he could complete this class. Later on, he wanted to continue study graphic design. Because this class did not require using dangerous tool, regional center did not approve the assistance to assist A.L. anymore. By then I realized I signed a service contract which has a condition that the approval of teacher personal assistance is subject to a dangerous tool is needed in the class. Your service coordinator might have explained to me on the phone. I was at work and was happy to know that a personal assistance was approved to help A. L. at college. Thus, though my English is limited and did not understand the condition of the service approval, I signed the contract. Now even PCC requests a personal assistance for my son to attend the class, my request to regional center to fund for personal assistance was denied. There is no help and support from regional center for my son to attend PCC.

I hope you understand our Chinese culture that we tend to trust and depend on you as a professional who will help our children to reach their needs. Our culture does not like to questions others a lot because questioning a professionals/government agency is considered unrespectful.

I really hope you will sincerely help us understand the content of the contract. I hope you will translate the contract and document in Chinese and the translation will be in good quality which is understandable to us. Let's help our kids to study and grow better. Thank you.

This is Sharing living in Arcadia. One of my two boys has Autism. He is 14 years old and has been with San Gabriel/Pomona Regional center for 12 years since age 2 and half. Before complaining. I would like to thank Regional Center's helps with our boy for these years since day one when I felt helpless and hopeless.

Speaking for many Chinese families who don't know English well, I have several issues with our own regional center mainly because I feel you don't have the voice for the Chinese community inside or outside your center.

First, I didn't see any information or links in Chinese on your home page. So many Chinese speaking parents have a hard time to find the useful information from your home page.

And, the workshops in English you provide are always at the terrible time of the day when our kids who have special needs are at home, when the traffic is horrible, when the location is far from our community! The point is that Dinner time is very important for Chinese families. Some of us live with our parents because of our culture and we as the primary caregivers are expected to be around or at home especially during that time when we need to prepare the meals or help our kids at homework or self skills. So for the past years, I always attend these Chinese-, time- & location-friendly workshops or trainings at East LA Regional Center location where my kid doesn't belong to and where you can not hear our voices!

I would like to see more events in the weekday morning when our special needed children are at school where we don't need to worry about so we can feel free to be educated by those events you provide. If the location is the problem for San Gabriel / Pomona Regional Center, I suggest you to work closely with CPAD where is located in the Chinese community. Or Parent's Place in West Covina or other locations where are closer to our Chinese community so more Chinese parents can attend the events. Let both sides' time and effort be worth spending!

And, hopefully we can see more links on your home page in Chinese so Chinese parents will know where to look for information. And the e-mails in Chinese about the upcoming events can be useful to the Chinese-speaking families.

Please Don't let our Chinese families sit in the dark! Reach us! Hear our voices by different channels (such as CPAD, school districts or Doctors practicing in our Chinese communities)! Don't let your time, money and effort be wasted! Together, we can make our community better and make our kids better!

Hi! My name is some Charle, mother of 2 adult sons with autism. Both have been the consumers of the San Gabriel/Pomona Regional Center since 1995/1997.

My concern is that people with disability from Chinese community often times are denied the service of independent living skills training because they live home with their parents. They need the independent living skills training although majority of them are currently living with their parents.

It is important that Chinese adults with disability learn to become independent as much as they are capable of. First, it takes a long time for them to learn and they should start the training as soon as the time is appropriate. Second, a lot of Chinese families, especially immigrants, do not have other relative families in or out of the state to fall back on when both parents are gone.

Regional Center must understand that Chinese parents are very protective with their children. It is a Chinese tradition to try to keep their children home even they reach the adult age. Therefore, it is not uncommon for Chinese parents to keep their adult children with disability at home. It actually would be a very difficult and emotional decision for the parents to let go of their disabled child before the time comes.

The training should start when the time is appropriate regardless of consumers living with or without their parents. The service coordinator should be able to help identify the need and make a recommendation to the parents. Having the training and living at home at the same time is more economical. The more independent they become, the less they depend on the outside help. This would be a win-win situation.

Thank you for your time!



## Apoyo a las Familias con Niños con Sindrome de Down Support Group Meeting on March 18th, 2016

## **Minutes**

Number of participants: 16 Spanish-speaking parents, plus the Clients' Rights Advocate from the local office of Disability Rights California. One parent was also a client of SG/PRC. Also in the audience was a Parent Support Group Coordinator/Outreach Coordinator/Family Resource Specialist for the Parents' Place.

Where: The Parent's Place Family Resource Center, 1500 S. Hyacinth Ave., West Covina, CA 91791

 This meeting was held at this support group's regularly scheduled location, and during its regularly scheduled day and time of meetings.

Translation: The meeting was conducted in Spanish by Rosa Chavez, Associate Director of Family and Transition Services. The power point slides of the disparity data were presented in Spanish and the printed handouts of the disparity data were also in Spanish. Printed copies of the English version of the disparity data power point slides were available.

Meeting Summary: The meeting was scheduled to begin at 4:00 p.m. However, most of the regular group participants were not present until 4:25 p.m.; therefore, meeting began around 4:25 p.m. Ms. Rosa Chavez introduced herself as the person who would be presenting the data. Other members of SG/PRC staff present were Yaned Busch, Manager of Family Services, and Carol Tomblin, Director of Information and Compliance. Ms. Busch was present to take notes and to help answer questions at the end of the meeting.

Ms. Chavez provided an overview of the meeting, that a power point presentation would be provided to guide the audience through the disparity data and that the purpose of the meeting was to hear the audience's input on the disparity data. The audience was provided handouts of the presentation for reference.

Throughout the time that Ms. Chavez attempted to review the information on the slides, there were numerous questions and comments from primarily nine (9) parents who had specific questions about their children and about eligible services. Although there was a concerted effort to redirect the audience to hold specific client-specific questions to the end of the presentation, and that Ms. Busch was also available after the presentation to take their information and note their concerns so we could address these privately, the parents continued to ask client-specific questions throughout the meeting. As a result, only about three selected slides were shown and Ms. Chavez attempted to answer the questions to the best of her ability.

Client Rights Advocate Aimee Delgado introduced herself and the advocacy services she can provide. She reminded parents that if they call her and cannot reach her to be sure to leave a message with their contact information so that she can assist them.

Below are the questions that were posed during the meeting.

One parent questioned why respite services were denied for her child who under 3 years of age. She reported that she had post-partum depression and other medical issues/injuries. This parent brought up this same issue several times. Regional center reminded parents that there is an appeal process if they do not agree with the regional center's decision. However, the eligible services and the appeals process under Early Start are different from the services and appeals process for clients over the age of three years.

This same parent was also dissatisfied with the services provided, specifically the occupational therapy services. Another parent added that the occupational therapist assigned to her child did not speak Spanish, but that she has not reported this concern to her SC. Ms. Chavez informed the parents that it is very important to contact their SCs immediately if they are experiencing any barriers in receiving the services that have been authorized.

Another parent shared that her child is under 3 years old and has significant medical needs, including being bed ridden. She would like to review eligibility for respite services. This parent brought up concerns about respite agencies not having qualified staff or staff available to meet her child's needs. Ms. Chavez encouraged parents to contact their SCs immediately if the respite agency is not able to meet the parents' needs.

A third parent expressed concern that her Service Coordinator (SC) referred her to the school district to request funding for occupational and speech therapy services; and then the school district referred her to regional center. Ms. Chavez clarified that generic resources, such as provided by the school district, must be explored/exhausted before regional center can fund.

This parent also expressed concern about SCs not being approachable or sensitive to their needs. Ms. Chavez emphasized the importance of feeling comfortable communicating with the Service Coordinator. She reminded parents that if they do not feel comfortable with their current SC they may contact the manager and share their concerns at any time. Managers need to hear from parents about their concerns. R. Chavez encouraged parents to contact the SC's managers and, if needed, to request a new SC.

On a more general note, one parent expressed that in her opinion SCs need additional training on how to explain services to families in Spanish. It is her opinion that SCs need additional training on all RCs services and they must have that information available at the time of the Individual Program Plan (IPP) meeting. She added that she feels that SCs are overwhelmed and not always available to provide the necessary information to families.

One parent added that she feels SCs lack sensitivity when notifying parents that they are not eligible for regional center Purchase of Services (POS) services. She would like SCs to receive additional training on how to communicate with parents why RC cannot fund the service.

Another parent stated that SCs need to be more knowledgeable in all regional center eligible diagnoses, including information on the expected development or milestones for a child with disabilities. The SCs

need to share with the parent what services would be most appropriate for their child at the time of the IPP. The parent suggested that SCs bring all this information in writing to the IPP meetings.

Ms. Chavez reviewed available parent training about services for children with Autism and their development through APEP program. One parent responded that she attended the APEP training because a parent informed her, not her SC.

Both Ms. Chavez and Ms. Tomblin informed parents that their input is very important and encouraged them to provide their input on what trainings they find useful currently and what trainings RC should provide for them in the future.

At this point, a couple of parents suggested that the regional center develop a booklet or handbook with information about RC's available services specific information about when these services are appropriate to the client's age and diagnosis. Ms. Chavez informed parents that there is a one-page summary of services that has been developed and is being translated that will cover services based on age group. Once all of the translations are completed, these fact sheets will be distributed to families at the time of the IPP.

Ms. Chavez also reminded parents that they can review their concerns or need for services at anytime with their Service Coordinators. Parents may change the frequency of the IPP review or meetings as needed. Families don't have to wait until the regularly scheduled IPP meeting to expressed their concerns or need for services.

Regarding vendored services, several parents expressed their concerns. One parent stated that she is not comfortable exploring agency respite because it is very difficult to trust strangers. She added that most of the respite staff is not trained to work with children with disabilities and they arrive late or leave early. She asked that SGPRC consider allowing relatives who live in the home to provide respite services.

Another parent expressed concerns about agency respite staff leaving early or not showing up at all. She stated that agency respite staff is not available to meet family's needs. The parents feel that they have to work around the respite staff's schedule instead of the respite staff being available when families need them the most. This parent would like to see the respite agencies hire more qualified staff, as she feels the quality of service is too so low and they are not comfortable leaving their child with a stranger.

A different parent stated that she feels behavior intervention staff is not properly trained or are not familiar with correct Spanish terminology for behavior intervention. She requested a new behavior intervention staff member and was placed on a waiting list until the provider could hire more Spanish-speaking staff. The family requested a new agency was requested; but at this time, the family was told that all behavior intervention providers have waiting lists for Spanish-speaking staff.

Two parents stated that they were content with their SCs and appreciated the partnership that they have developed with their SCs. They shared that communication with their SCs was very important.

They agreed that parents should be able to contact their SCs any time to express their concerns related to their child's needs.

Prior to the conclusion of the meeting, a list of suggestions was developed about that the regional center should do to help resolve some of the concerns expressed by the parents.

- 1) Have a one simplified version of the POS policy. Parents expressed that the language in the POS policy is vague and difficult to follow. The Spanish language used in the translated version is not universally understood.
- 2) Simply the appeals process.
- 3) Provide additional training to Spanish-speaking SCs on the correct terminology when explaining services and supports.
- 4) Update the client handbook and use language that is easy to understand.
- 5) Provide on-going trainings at SG/PRC for parents in the following areas:
- the POS policy;
- available generic resources;
- how to navigate through Medi-Cal and private insurance for autism services.
- 6) Provide additional training for SCs on child development and for SCs to be more specialized on specific diagnoses, such as Intellectual disabilities, Down syndrome and Autism. Parents insisted that SCs need to become more specialized in specific diagnosis. That they provide more input to parents and what to expect from their child based on their skill level or cognitive ability.
- 7) Regional center to train SCs to make recommendations at the time of the IPP, as to what services are most appropriate for a family's child. SCs spend too much time reviewing paperwork instead of providing feedback on what services would be most appropriate for their children.
- 8) Provide additional training on IEPs and what "related " educational services are appropriate for their child.

The meeting concluded at approximately 5:30 p.m.

# Dad ROCKS Support Group Meeting on March 18th, 2016

### **Minutes**

Number of participants: 10 fathers of clients, one mother was present on behalf of a father who usually attends, plus, the Clients' Rights Advocate from the local office of Disability Rights California.

Where: The Parent's Place Family Resource Center, 1500 S. Hyacinth Ave., West Covina, CA 91791

 This meeting was held at this support group's regularly scheduled location, and during its regularly scheduled day and time of meetings.

Translation: The meeting was conducted in English by Mr. Ernie Cruz, Director of Community Services, and in Spanish by Mr. Cesar Cruz, Manager of Adult Services at SG/PRC. The power point slides of the disparity data were presented in both English and Spanish, side-by-side. Printed handouts of the disparity data were available also in both English and Spanish. Both Mr. Cesar Cruz and Mr. Ernie Cruz are bi-lingual in English and Spanish.

Meeting Summary: The meeting was scheduled to begin at 6:30 p.m. but began closer to 7:00 p.m. Ernie Cruz, Director of Community Services, and Cesar Cruz, Manager of Adult Services introduced themselves as the ones who would be presenting the data. Another member of SG/PRC staff present was Carol Tomblin, Director of Information and Compliance.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for reference.

Both Ernie Cruz and Cesar Cruz reviewed the information on each of the slides and responded to any discussion, questions and/or comments from the audience that was prompted by the information on the slide. Some basic information was shared, such as the expenditure data representing who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. Part of the presentation pointed out that there are disparities noted between ethnic groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic groups having the highest percentage of no POS expenditures compared with other ethnic groups.

The audience was encouraged to provide input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers to clients receiving authorized services or utilizing services, as well as any ideas to remedy these barriers.

SG/PRC also shared changes in procedures that are being implemented in response to previous feedback from families. It was presented that SG/PRC has developed a one-page fact sheet, or POS summary, indicating services that are available by age group. This information is currently being translated into

several languages. The audience was told that once all of the translations are completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future.

The audience was told about another change that began March 1<sup>st</sup>. SCs and their managers started receiving reports of clients' authorizations and utilization for each quarter so that SCs can confer with families if the SCs observe that the clients'/families' utilization is less than expected.

The following is a list of questions or concerns that were raised during the course of the presentation.

One father was concerned about the large caseload ratios and how that affected the quality of case management services. He stated that he felt that these high caseload ratios contributed to the service coordinators not doing their job of getting needed services for clients.

A question was raised about how the regional center budget was decided. It was explained that the regional centers receive an "allocation" rather than a budget per se, based on anticipated costs. It was recommended that it might be helpful for future presentations to provide a slide to help explain how the regional center funds are allocated. This discussion also included a concern about what happens to the funds that are allocated but not expended or utilized, and a question was asked if these funds could be "rolled over" to the following year.

In reviewing slide number 8, one parent requested that it would be helpful to know the age of the parents when discussing "living with families".

Also related to slide number 8, one parent requested that information about the clients involved in the legal system that were between the ages of 18 and 22 years. There was also a concern about the number of clients who were involved with the law before the age of 18 years.

Although there was acknowledgement that Latino families most often desire to keep their loved ones at home – and that this may be true in general – one of the audience members pointed out that the newer generation of Hispanic families may not believe that keeping the clients in the family home is the best for them. This particular father stated that he had goals for his children to live and work on their own and not stay at home. The conversation continued that regional center should not assume that Latino and Asian families always want to keep their adult children at home. There was a concern that the regional center would not develop sufficient residential services, independent living, and other resources if we simply accepted this assumption.

There was another question about if there was sufficient planning and resource development to meet the needs of the large school-aged population in the Hispanic and Asian groups served by SG/PRC who will be aging out to adulthood.

In terms of further analyses, there was a question whether the statistics for SG/PRC mirrored the rest of the regional centers in the state. There was also a concern about whether the percentage of the people served by SG/PRC was representative of the whole community covered by SG/PRC's service area. The parents stated that they would like to know the numbers of people by ethnic group in each city served

by SG/PRC. A brief conversation followed about when and how often the census is taken and trying to get accurate data for the SG/PRC area.

When we got to slide number 17 and 18, it was suggested that we highlight the percentage of POS utilized.

There was a discussion about self-directed services (previously called self-determination at ELARC). SG/PRC staff provided information about the next scheduled advisory committee meeting.

Some parents expressed that they have received literature from the regional center written in Spanish, but that they have had difficulty in comprehending what was written.

It was expressed that there may be a number of Spanish-speaking families who are undocumented and that they are not requesting services — or may refuse to receive services being offered — because of their fear of deportation. Some emphasized that we should not discount the fear factor in how it affects the potential utilization of regional center services. Some families may not appeal a denial of services because of this fear factor.

There were some specific concerns shared. One Spanish-speaking father expressed a lack of response from his assigned service coordinator (SC). This parent was encouraged to call the manager and leave a voice message in Spanish. Even if the manager of his particular SC was not Spanish-speaking, the regional center has many managers who do speak Spanish, can translate the message and help resolve the parent's issues.

Another father of a two-year old discussed his concern with dealing with the school district. He was advised to discuss with the assigned SC so that the SC could provide him assistance and advocacy at the IEP meetings.

Meeting concluded a little after 9:00 p.m.

## Fiesta Educativa Support Group Meeting on March 22nd, 2016

## **Minutes**

Number of participants: 31 people, including the Clients' Rights Advocate from the local office of Disability Rights California and the Executive Director of Fiesta Educativa. The audience primarily consisted of parents of SG/PRC clients. One parent was visiting from Westside Regional Center.

Where: La Puente Community Center and Youth Learning Center, 501 Glendora Ave., La Puente, CA 91744.

 This disparity presentation was scheduled during Fiesta Educativa's regularly scheduled date and time of their meetings.

Translation: The meeting was conducted in Spanish by Ms. Edith Aburto, Manager of Family Services at SG/PRC. The power point slides of the disparity data were presented in Spanish and the printed handouts of the disparity data were also in Spanish. The English version of the power point presentation was available. Ms. Galarza was also available to assist by answering questions in Spanish.

Meeting Summary: The meeting was called to order at 10:00 a.m. Edith Aburto, Manager of Families Services, was introduced as the person who would be presenting the data. Other members of SG/PRC staff present were Lucina Galarza, Director of Client Service, and Carol Tomblin, Director of Information and Compliance.

A power point presentation was used to guide the audience through the data and related charts updated from prior year meetings and to engage the audience in additional discussion/input. The audience was provided handouts of the presentation for reference.

Ms. Aburto reviewed the information on each of the slides and responded to any discussion, questions and/or comments from the audience that was prompted by the information on the slide. Some basic information was shared, such as the expenditure data represented who received Purchase of Services (POS) funds from SG/PRC, only. Expenditures paid by other sources, such as Medi-Cal for Intermediate Care Facilities (ICF) residents, were not included. Participants received information about "payor of last resort"—and who is responsible for services, depending on age of client. For example, it was shared that after age 22, the regional center becomes more responsible for funding services.

The difference between authorizations and expenditures (i.e., utilization of authorized services) was explained. Part of the presentation pointed out that there are disparities noted between ethnic groups in terms of NO Purchase of Services expended, with the Filipino and Hispanic

groups having the highest percentage of no POS expenditures compared with other ethnic groups.

The audience was encouraged to provide input regarding what SG/PRC could do differently to help make the POS authorizations and utilizations more equitable. The audience was asked what they saw as any current or potential barriers to clients receiving authorized services or utilizing services, as well as any ideas to remedy these barriers.

SG/PRC also shared changes in procedures that are being implemented in response to previous feedback from families. It was presented that SG/PRC has developed a one-page fact sheet, or POS summary, indicating services that are available by age group. This information is currently being translated into several languages. The audience was told that once all of the translations are completed, they will be posted to the SG/PRC website and handed out at meetings between SCs and families beginning in the near future.

The audience was told about another change that was implemented March 1<sup>st</sup>. SCs and their managers started receiving reports of clients' authorizations and utilization for each quarter so that SCs can confer with families if the SCs observe that the clients'/families' utilization is less than expected.

Throughout the presentation, a number of suggestions and comments were provided by the audience, indicated below.

An audience member indicated that the handout of this meeting's power point needed to be made with bigger print. Parents indicated that they were unable to read the chart labels in the printed material provided, although they were easily able to read the presentation displayed on the screen.

Families want to have the Service Coordinators (SCs) to be able to explain what services are available for their family, even before they start asking about the client and client's needs. Many families indicated that they wanted to have more information about available services.

Families expressed that the regional center needed to provide additional training to SC's, so they know the services they can provide to the families/clients. Families also said that they wanted to have a better understanding of what the regional center cannot fund, and the reasons for not funding.

Likewise, they want the regional center to better train SCs, so they don't deny services without offering a chance for family to appeal the decision. For example, one parent stated that when they asked for OT/PT/Speech they did not get a chance to appeal. Another parent said that their SCs talked about goals for the client, but then said that the regional center could not or

would not fund the services that would help the client achieve the goals. . Another family member said that when the SCs said "no" to a service, the SC did not tell the family what services the family/client did qualify to receive. The family indicated that they were not offered other options.

Participants asked about the SC's involvement in the Individualized Education Program (IEP) process. They asked "at what point" can the SC speak up at an IEP meeting. Parents shared that their SCs are quiet at the IEP meeting. It was explained that SCs are there to support parents. Parents were also told that they can receive training on how to advocate for their child. Parents were told that RC can pay for conferences for them to help them learn how to better advocate for their child.

Parents asked about respite services and how they can qualify for this service. Regional center staff provided a brief explanation.

Parents expressed a concern about the availability of vendored staff and lack of options provided to them. They reported that SG/PRC SCs did not give them options in terms of different providers. It was reported that the SCs just provided the families with one option and that the SC would assign that vendor to provide services.

Families expressed a concern about the oversight of vendors by the regional center, on how vendors are providing the services. Families reported that vendors are not consistent in the way they provide services: some vendors are very strict, while others are flexible to meet the client's needs. Parents reported that there is a lot of abuse in the part of the vendors. (Unfortunately, SG/PRC did not receive more specific information that would have allowed us to investigate and follow up with corrections.)

Parents expressed that they are worried about their children's safety, specifically when they are to transition from school services to work or adult day program services.

Parents in the audience indicated that there are workshops offered to parents with children with Autism (like APEP) to educate those parents how to better work with their children's behaviors. Similar workshops are not offered to families of children with other diagnoses.

In addition, it was suggested that behavior workshops, adaptive skills workshops and other trainings need to be offered in different geographic areas, not just at Regional Center in Pomona. Parents shared that the office location was too far for them to travel; some have transportation problems.

Parents wanted to know what services were available for those clients that live in the home with the families. It was discussed that a fact sheet with information regarding typical service available by age would be available soon in a variety of languages.

Parents wanted to know more about self-directed services, specifically to fund for aquatic therapy and other therapeutic/recreational options.

The meeting concluded at approximately 11:30 a.m.

# Clients Living at Home - All Ages

