



**Tri-Counties
Regional Center**

ATTACHMENT D

2016 POS Expenditure Information Night

Tri-Counties Regional Center

PARTICIPANT SUGGESTIONS - ORGANIZED BY THEME

Age

- 1 Are families ready to talk about transition at age 14? It's a big issue.
- 2 Highest amount of expenditures is with the adults.
- 3 Transition services - look at the "what if's" when planning options.
- 4 What is going on with the Native American population? It's the only culture that is showing flat line for the past three years. There is something more to it. After 22 aren't they going anywhere?

Communication about services may be inadequate

- 5 0-3 families are referred to the Parents Helping Parents but after 3 they don't know if individuals are still served by the Regional Center.
- 6 A lot of people who are eligible for IHSS but does Regional Center staff know about how this works and how to guide family? Lack of information given to families and those served by Regional Center and staff.
- 7 Changes in funding need to be made clearer.
- 8 Difficult to get information on housing.
- 9 Do people know what their choices are?
- 10 During early years it's hard for parents. Need repetition. Moved from another RC and things were different. Didn't understand Medi-Cal and it took years to have son eligible. People don't get entitlement. Help parents make sense about why a certain service would be good. RC to be more involved in helping parents more.
- 11 Families do not understand what RCs do and how they work at different age stages.
- 12 Figure out a way to reach out to everyone served to get their input.
- 13 Find different ways to get the information because not everyone answers email.
- 14 How can information be gathered regarding available services?
- 15 Latino community shares information to each other and sometimes it is misinformation and creates fear; the information may not be correct.
- 16 Menu of services needs to be more available and clearer.
- 17 Need to identify what services are really needed and wanted. Present the information about services in a culturally respectful way so families are not hesitant to access what services are needed.
- 18 New service coordinators that are more experienced are not going out to provide more information.
- 19 Orientation to reflect what services are available.
- 20 Our son is currently receiving ES services but don't know if he will be eligible once he turns 3. His hearing is fine but there are signs that show that I believe he might have autism. Therapist says it is his sensory deficit. I want my son to be like other 3 year olds but he can't speak like other 3 year olds. He tries to talk but when he can't, he screams. What is out there as far as services?

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- 21 Parents Helping Parents is underutilized by individuals over 3 yrs.
- 22 Regarding the Family Orientation it should happen at every different stage of one's life; whether it is video, or live meeting, brochure. People come to CHANCE Housing without knowing what for example Medi-Cal is or knowledge about what generic resources are available (i.e bus pass). Increase information to families about services they qualify for (i.e generic resource that exists for the betterment of that family). People go homeless because they lack the income and information.
- 23 SC needs to consistently share information across our agency to individuals and families.
- 24 See what's out there is important. As new programs become available it is important to know what is in your area.
- 25 Spanish families-not sure they know what services are available.
- 26 The answer of "We don't do that" needs to be followed up with ..."but this is what is available and who can fund it..."
- 27 The question of "What is available?" is often asked and the answers are different.
- 28 Training on presenting services more effectively.
- 29 We need more information on service available. It needs to be explained to us in different ways.
- 30 You don't know what you don't know.
- 31 (SP) Mariana stated that it appears to be not language barrier a communication due to lack of information of services. SC not appearing to take a real look at needs and get to know families to find out what needs are. Some situations may be due to families not informing SC of needs.
- 32 (SP)Mariana stated that known services /information are needed in order to keep individual at home.
- 33 A parent was told that there was nothing for her daughter after high school.
- 34 Could it be that there is more information available in English?
- 35 Our needs our being met. We didn't realize there are so many programs. It helps out a lot.
- 36 Sometimes information does not come from coordinators. This evening is an example.
- 37 There needs to be better communication for those served by the RC who are in foster care to be sure all of their needs are addressed including durable goods.
- 38 What resources are there after high school for those that don't want to continue school until the age of 22?
- 39 SLS coaches have info on other resources that people might not be aware of. Educate Spanish people about these.
- 40 Should the coordinators direct the parents as to what services are available for their children?
- 41 Different diagnosis may impact variances.
- 42 Have concerns about dual diagnoses - mental health and autism - need additional services.

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- 43 Transitioning from the MH system to TCRC last Oct; just now beginning to receive supports.
- 44 My daughter is 43. In the 1970s we had to have specific diagnosis. We don't want to give a diagnosis to an infant because they will always have that in their record and it may be very inaccurate. Other times we don't see signs/symptoms until the child is much older. Most undiagnosed RC clients are under 3 years old. People who are further along in development are easier to diagnose/evaluate.
- 45 Newly diagnosed need increased support. Have more orientations designed just for them.
- 46 Sometimes people at age 3 look like they might have autism, so we accept them under 5th category because other things are playing a part in potential long-term diagnosis. We can evaluate better when they are older.
- 47 Would we expect no diagnosis and autism to remain same in future? Not sure, some 5th category cases remain so. There are other diagnoses that are similar to or require treatment similar to Intellectual disability. They are unlikely to change a whole lot. Much less CP due to fewer birth injuries and better prenatal care. Some people receive services and get degrees, jobs, live independently.

Economic, Social, or Geographical Differences

- 48 How data reflect the actual demographic areas?
- 49 Demographics from county to county are all different.
- 50 I think we need to evaluate each community according to what they are. Agricultural area: We have families that in the past have worked the fields. They used to work two seasons but now they only work one and are having to leave. In SM we have 75% Hispanic, 20% Misteco. Don't speak Spanish, don't read or write. Increased shared housing. Families living with families in single household dwelling. Some families don't want therapists in their home; their home disrupted. Four or 5 people to a room. They encourage baby to be quiet rather than develop language skills cause they have to live a multi-family home. Any professional is seen as an authority figure. The cultures are so varied and the norms so different. Different community cultures within our county.
- 51 Is residence related to funding other services?
- 52 Confirms our experience; expenditure data. At CHANCE housing we look at holistically the individual including regional center services looking at obstacles and opportunities regarding housing. We have implemented a process out of necessity for the system to document unmet needs. If the Regional Center knew about their needs we believe that their needs would not be unmet. We believe we know why the variances are present; Hispanic community persons live with their family, catch 22 regarding financial situation, lack of knowledge and generic resources that service coordinators struggle to stay on top of.
- 53 Other ways to get information to families in an understandable way; we do not have the expertise to figure out information and technology, nature of the disability and the poverty level does not lend itself to.

Education Levels Vary

- 54 Families will not read the information, or brochures, they may not have the basic education to understand how to read.

General Cultural Differences

- 55 (SP) The group felt that Hispanic women tend to not want to take a break for themselves or take care of

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themselves. Building a relationship with the mom and supporting her to use services to take a break is very important.

- 56 (SP)Mariana asked why less funds are spent on Hispanic clients. Eulalia explained that generally Hispanic families have a tendency to remain together and keep individuals at home. This is an area where more ideas are needed. Mariana agreed that this is a cultural issue and that parents tend to think or see as odd that respite is needed and may feel that they are a bad parent and that it appears that Caucasian families do not feel bad in accepting respite hours. Alpha is trying to support the Hispanic families and not feel bad about respite and utilize the hours in order to take care of themselves(ie: feeling bad about getting help, self-care). Mariana emphasized the importance of SC getting to know the families and for parent to not feel bad in requesting help and services.
- 57 Cultural differences regarding goal for independence vs "family taking care of their own.
- 58 Cultural differences should be taken into consideration.
- 59 Focus on cultural sensitivity and competence.
- 60 For those residing at home parents are more likely to hold onto them, not encourage them to live elsewhere.
- 61 Hispanic predominantly keeps their relative at home and care for them, so the cost is less.
- 62 How to involve the male figure of the Hispanic household?
- 63 Is there a cultural reason why some live at home?
- 64 Latino mother: stated that I want to do everything I can for my son first before I seek help from someone else. I don't feel comfortable having someone do the work that I am supposed to do as his mother.
- 65 People do not like people they do not know coming into the home, especially when there are sensitive things like diaper changes.
- 66 Some Hispanic families prefer to take care of their own internally within the family structure and rely on other siblings or extended relatives to care for their child; they feel responsible for their own.
- 67 What kind of advocates families are in terms of services; expectations of the family, less expectation on Hispanic families. Caucasian families may feel a greater sense of responsibility.
- 68 A couple of reasons in which there may be disparity is that in the Latino community we tend to care for our own and disabilities in our family is not commonly talked about. There is stigma around that area. Another reason may be that we are not fully aware of the services that are provided once we are with the regional center.
- 69 SP - Annual conference called Walking the Path. This is something traditional in Ventura County done with SELPA and TCRC. In the last year and a half it has been cancelled due to poor attendance. The Spanish families do not register using Internet; they do not register 2 months in advanced. This does not acknowledge the way the Hispanic population goes about organizing their schedules and does not represent those that would attend.

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Immigration Issues for Undocumented People

- 70 (SP) Mariana explained that some parents are fearful of accepting services due to their immigration status.
- 71 Hispanic families fear about legal or illegal status; they may not ask about services because of fear of being reported to ICE; they are so thankful for services offered, they do not speak up; half the reason is because they do not know any better.

Language Hurdles

- 72 Are vendor packets translated? If not, why not?
- 73 How do people that are Mixteco identify themselves-Spanish, other Latin?
- 74 Look closer at family members and circle of support to make certain that a bilingual SC is identified for that person even if the individual identifies themselves as English speaking if they have Spanish speaking family.
- 75 Menu of services in plain language in Spanish and training.
- 76 More funding for family resource centers to hire bilingual staff would help.
- 77 More information in the preferred language, radio stations, more frequent visits, SC spend more time with families especially monolingual and bilingual.
- 78 Perhaps those that know and speak English are better at finding resources.
- 79 VMRC translates vendor packets to attract different cultures / ethnicity.
- 80 What are service coordinators doing to meet unmet needs of the Mixteco families who speak various versions of the language? TCRC has numerous interpreters but the various versions of the language can make this difficult.
- 81 What is the ethnicity type of vendors? Do we track this? If a person is Spanish speaking and the vendor only speak English, they won't go there.
- 82 Bilingual specialists to help parents at FRCs. Support groups especially parent to parent is so critical.
- 83 SP - Have an interpreter present at board meetings.
- 84 SP - There is a difference in between the quantity and quality of written materials between what is in English and Spanish.
- 85 In Santa Maria and Santa Barbara counties many migrant farm workers may be losing their jobs and CHANCE expects to have a higher number of referrals by these families who may speak Mixteco language.
- 86 SP - The difference between socio-economic and education between Hispanic and White is big in our catchment area. Hispanic persons get information by talking to one another vs internet or email.
- 87 When you look at the pie chart at look at the greater amount of those living at home, what is sticking out to me is that we need to use plain language, spell it out. Push the envelope if we would focus at using plain language.

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Parking Lot - Miscellaneous Comments or Questions

- 88 (SP)Mariana explained to parents that if they ever see someone such as neighbors or friends have children that appear to have needs.
- 89 (SP)Right now Mariana feels that language is no longer a barrier for equal access to services to the regional center (lots of bilingual).
- 90 A lot of info to absorb.
- 91 Accessible Uber drivers who are knowledgeable and have a background check.
- 92 Advocacy is a good tool to bring providers together to act as a group.
- 93 Anytime I call I get the help I need.
- 94 Are families choosing to opt out of services?
- 95 Broad subject would like to see outcome of the survey; would like to understand this more.
- 96 CHANCE is talking to Marty Omoto about the state doing an unmet needs request; if we start to collect the information via the referral packet can share this information.
- 97 Community health centers provide good mental health services, why can't TCRC people receiving services access services at mental health?
- 98 CSLS is a real leader in the state - ARCA needs to recognize their contributions - why aren't RC staff attending their meetings and conferences?
- 99 Define variance.
- 100 Disparity of services is across board like education.
- 101 Document and ask the right questions look at the data and make sure we are comparing this accurately is there equal access to choices. Are we comparing the same things?
- 102 Does TCRC look at the information by county?
- 103 Educational to hear this information
- 104 Email or phone.
- 105 For those living at home, the fewer people who are involved in the person's life, it's more telling them what to do.
- 106 Glad that TCRC is working on orientation for families
- 107 Hears that TCRC making funding cuts and glad to hear that funding is being utilized.
- 108 Hiring staff by providers is difficult - a lot of traveling required and mileage reimbursement is low.

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- 109 How can we communicate with you?
- 110 How can we get providers to participate in these meetings?
- 111 How much time was spent collecting the data versus time spent with the families?
- 112 Humanizes the information?
- 113 I was one of the original parents to help initiate the Lanterman Act.
- 114 I wonder at what age they diagnose autism? Before age 3? Why or why not?
- 115 If client not diagnosed with a specific thing do they get less services? Not necessarily, services are based on need.
- 116 In 2004 I (parent) purchased a house for my daughter and I hired staff and they have been incredible, (PCS). I wanted her to have a quality of life and ever so often we meet and discuss services, sometimes it does not go smoothly but life is that way. She formed the Coalition to preserve the Lanterman Act; next major push is to get more money for direct support professionals to get decent pay. Minimum wage increase with no money to back it how will this be done? Omar is a top Exec out of all 21 Regional Centers; this is the best regional center and Omar and TCRC reputation is this way across the state.
- 117 In order for RC to purchase services, must people be vendored? Yes, all providers must be vendored.
- 118 Information real helpful. You have been there for us. Our coordinator is wonderful and always answers our questions.
- 119 Interesting that the amount spent on SLS is so small.
- 120 Introduce vendors to those served to learn more about what is out there, what will be the best fit.
- 121 Is there a national database? Don't think there is one. Some national core indicators such as NCI. Not as comprehensive as the Sandis data we collect.
- 122 Is there a way that the regional center provide a vendor demographic information for persons that are referred?
- 123 Is this a variance or is it a disparity?
- 124 It is critical that we support our legislators and call them when we have a concern every parent who is involved makes the difference. Go visit legislative offices. Call and thank them.
- 125 Made me feel secure to see the behind the scenes.
- 126 More centralized community resource library.
- 127 More data.
- 128 My instructor who helps me at my day program has been ill.
- 129 My son is too hard to care for, he cannot communicate easily; he always smiles I cannot live without him, he is a happy boy. My coordinator and manager (Azita) helping us to get a different bed for my son; they are

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very good and I am very glad.

- 130 NCI - provider appreciates PCT - all staff are trained in PCT and it works wonderfully for their company. So glad TCRC is spreading it to others.
- 131 No diagnosis in our system is our Early Start program, which does not require a specific diagnosis to qualify.
- 132 Not much, I am just here listening and learning.
- 133 Our daughter has lived with us for all of her life and there was no help for her early on, she has two sisters, they help when we can and we the parents need help. Don't know what help I need to have her continue to live at home, parents are older and tired. Parents have gone through major health issues and are still struggling health wise and our daughter has additional health needs it is hard. We had help and it stopped and we did not know why. The provider wants to come when they want to come not when we need them. Take the service when we get it; it would be nice to have an agency that wants to help people and would be available- more responsive to our time and needs. We do not need anyone to take her out for recreation - we need respite care.
- 134 People want information - as part of the strategic plan staff will be collecting information from individuals and families served.
- 135 People who are not eligible for Medi-Cal services - is there a budget for purchasing counseling?
- 136 Report the demographics of the city.
- 137 Someone may look like they are receiving supports that are not needed but you never know what their needs would be if they did not have those supports.
- 138 SP - The Hispanic persons or parent leaders are being groomed to have more leadership roles.
- 139 SP -Allow the board member to participate via video or phone conference.
- 140 Spending less does not mean quality is less.
- 141 System underfunded for a long time, new service coordinators, big caseloads.
- 142 TCRC has an employment coordinator that is not available to persons served at other Regional Centers. This is a positive thing.
- 143 TCRC is doing a good job with transition fairs.
- 144 The Native American numbers just don't make sense.
- 145 The presentation of the data creates expectations of change.
- 146 Tonight venue good presentation.
- 147 We are trying to add positions based on # of people served. State just approved a budget increase on July
 - We're looking for quality people and sometimes we can't settle for the applicants we have. We need knowledge, responsibility, compassion, bilingual. Recruitment is increasingly challenging. Cost of living high here and pay is 20% lower than comparable jobs.

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- 148 We need more information about the persons served to interpret the data.
- 149 We need the results of the study that USC Children's Hospital has been commissioned to do.
- 150 Westside has a grant.
- 151 What about a regional in Santa Paula?
- 152 What does it leave unanswered?
- 153 What is TCRC doing to reach out to those transitioning from school out to adult?
- 154 What is the true variance a result of?
- 155 What would families say? Can they make relevant and useful to them?
- 156 Who puts the data out? Comes from DDS but is based on information TCRC puts in.
- 157 Why does the caseworker have such a heavy load; so many cases? Budget - this money is different than the money we're talking about tonight. Tonight we're talking about purchase of services for individuals served. Budget for hiring is our operations budget, totally different.
- 158 Why is the data varied? Is it cultural? The why is missing as to why data is different.
- 159 Why is there a disparity within the Hispanic community?
- 160 Why isn't PCT required throughout the system?
- 161 Would regional center staff take suggestions from others (stakeholders, providers, etc) that may help them meet the needs of those served? Would they take the input respectfully?
- 162 Can we make mental health more accountable to assist with providing services?
- 163 Do these costs include medical costs?
- 164 Why are there greater costs in the older group?
- 165 Do people need less help if they speak Spanish?
- 166 Less graphs, stats and more conversation.
- 167 Why do they not separate by level and capability? Why is everyone grouped together at that age?

Other

- 168 Change RC operating hours to include Sat morning and late Friday evenings to accommodate working individuals.
- 169 Data seems to be clear. Ask the question about living at home : is it a preference as opposed to living under a bridge ? How this question is asked might change the answer. Ask more indepth questions when seeking data regarding satisfaction of services across race and ethnicity.
- 170 Some families might not fully understand what benefit they can see from accepting the services.

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- 171 Understand what the need is for each family. Are we offering services that are needed?
- 172 Transportation is a problem in our area. We need better transportation. Weekends hardly any service; horrible. Affects ability to get and keep jobs.
- 173 I have a vendor that does not provide all of the hours they are authorized for. Are they billing as if they are providing all hours? This would increase the overall POS if vendors are not accurate.
- 174 (SP) Making home visits and connecting with the family and the child is very important.
- 175 (SP) The group felt that they learn best about what services are provided by a regional center if they have a
- 176 Give people more freedom to choose, not enough vendors to meet? Providers feel pressure to meet needs?
- 177 What is the RD team doing? Are they looking at vendors that are from different cultures? Ethnicity?
- 178 People might need opportunities for activities...not respite just to address their needs. For people who live at home, it is hard to find the right people; is also difficult.
- 179 I hope that more probing will go into the question of do you want to live at home. What if it's only better than living under a bridge? We need to look deeper.
- 180 Important to identify if people who report liking living at home are really expressing their preference.
- 181 My daughter moved to an apartment and I was appalled by the supports that her roommate received. She was basically babysat.
- 182 How can we increase advocacy efforts for family advocates?
- 183 Establish more support and trust within the community so families know it is safe to share openly.
- 184 Sometimes people answer differently if their family members are present.
- 185 This information needs to be shared with more people. Why aren't more Latino families here?
- 186 I'm glad there is more information available to families these days than when we first got our daughter diagnosed.
- 187 For adults served reach out to the day program to get input to have more accurate data to interpret
- 188 If it becomes available we need help (elderly parents) for 3 weeks to attend to a surgery and still care for our older daughter. The question is where is the help? We have talked to the service coordinator about this does not appear to be resolved. We parents need to make contact the coordinator to discuss current concerns.
- 189 Why do we not spend more on services for people who live at home with their parents especially for adult children. Can we take a look at why we do not spend to support people to live at home?
- 190 Serve me better by more transportation access/choices.
- 191 Trust is an issue especially when individuals turn 18-that is the scary time to explain to parents and

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prepare them for the transition. Building in information about self-advocacy.

- 192 Need to do outreach to parents re: stress management, outreach to Hispanic community, relationship enhancement.
- 193 There are a lot of parents of those we serve that own businesses, have friends that do. What are we doing to reach out to them to see if they would hire those we serve?
- 194 I would want to learn more about services; this POS meeting is helpful and I got a lot of information. Parents sharing information with each other; learning from my friends.
- 195 Reassuring families that they will always be included as part of any planning that occurs with their adult child; part of the planning team. Asking the right questions is important.
- 196 Can data be broken down by city?
- 197 Can data be broken down by County?
- 198 Can Kinetic Flow data help or support variance?
- 199 Re-visit communications for the POS meetings; are they in simple language that anyone could understand? Do people really understand the purpose, how this would benefit them, what they will get out of it? How is the information being distributed? If it is email some or many persons or families may not have access or may not be able to read?
- 200 I would reword the question "What can TCRC do to ensure that services are delivered in an individualized and culturally competent way?"
- 201 Slides representing our satisfaction data needs to be included in the presentation
- 202 Use plain language when presenting.
- 203 How does TCRC gather this data?
- 204 Is the data from survey?
- 205 What is the percentage of the area that is measured?
- 206 Why is broken up by ethnicity?
- 207 Can regional center please consider modifying referral packet to include demographic data?
- 208 Can we get data on those who are dual dx with mental health dx? Currently we do not have a way to track this because we are not a mental health system we serve those with dd. We can mark psychotropic
- 209 Include the homeless in residence.
- 210 SP - It is important to have Hispanic leadership to guide the future activities and services of TCRC.
- 211 SP - More representation on the board of Hispanics can be accomplished by allowing a member who is monolingual Spanish speaking to have an interpreter.
- 212 Do service coordinators and other related departments understand what the POS Variance data really is and how to explain the importance of this to those they serve?

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- 213 Translate vendor packet. Reach out to culturally distinct groups and organizations and try to recruit vendors from those groups.
- 214 Include information regarding what has the Regional Center done between presentations.
- 215 SP - In Early Start there is a lot of persons that speak Spanish, so the information is pretty equal.
- 216 The relationship with the SC is important and critical.
- 217 (SP)Lack of transition services information. SC not attending IEP's even though SC invited. Parents request change because perhaps services that are offered don't meet the need.
- 218 Challenge is to not go outside the scope of what the agency is charged to do by the state.
- 219 (SP)Some parents do not know who their SC is. Parents are a little frustrated due to not knowing and many changes of SC.
- 220 Are services being spent more on those that "push" harder?
- 221 It's the squeaky wheel that gets the services.
- 222 Can data share how many people do not claim a residence are homeless? If you have a child who resides with a family that is homeless is there a way to indicate this? Do they physically live at home, or are they living in a homeless shelter, car, street or shared living situation?
- 223 Look at where individuals live, i.e with parents, residential facilities.
- 224 Promotordes model locally...families talking to other families in community.
- 225 Better communication between agencies, school districts, etc.
- 226 Figure out a way to break down obstacles for families that are reluctant to accept the need.
- 227 ILS expenditure and SLS expend should not be combined as there is a limit to ILS - SL could be misleading.
- 228 Looking at the data, we found that those who are 22 years or over, TCRC serves 3,114 white adults and 1,499 Hispanic adults so when we look at why we are spending more for the white population we basically have twice the number of white adults than Hispanics. If we doubled the amount we spent on Hispanic community we would be close to even. We really are not spending more on the White vs Hispanic community.
- 229 You need to talk to the community and ask them directly.
- 230 Family plan is hard to understand.
- 231 It would be useful to offer training on IPP.
- 232 Why is there a variance by language?
- 233 Why is there not enough help for older clients?