FORMAL & INFORMAL COMMUNITY SUPPORTS

- Ranking (Total/SA/FA) – pg. 3
- Raw Narrative Responses
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- Raw Narrative Responses
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FORMAL & INFORMAL COMMUNITY SUPPORTS

Rankings based on average scores on a 1 - 11 scale (1 = Most Important)

Total Ranking = 5th

Self-Advocate Ranking = Tied at 5th

Family Advocate Ranking = 3rd
FORMAL/INFORMAL SUPPORTS

Question 1: Why did you put this as most important to you?

1. From a regional center perspective, huge need for education, and awareness of generic resources.
2. Medi-Cal, IHSS. Funding to keep the programs running, that's the most important to me.
3. Because of my health insurance. I couldn't afford it without MediCal.
4. Healthcare for all
5. This is basic and critical mission
6. MediCal help provide health insurance for them. IHSS helps our sanity to be able to have help
7. Because my child has a rare genetic disorder called PITT HOPKINS SYNDROME - only approx. 900 worldwide only 2 in Southern California. My child is one of them. Doctors and professional team never had a case like my son so we the parents are the experts. It's very FRUSTRATING
8. My child is young, and I want to learn about those topics
9. I think that a lot of our consumers do not access resources that are available
10. Parent empowerment center
11. This is important to us.
12. Because we cannot get other services if we do not have medical
13. People don't know
15. If people around us are not educated, we can't move forward.
16. It gives the secure and peace for every family known that you have the support medical and economic to improve your health and self-being
17. Formal and informal community support provides a wide variety of opportunities that might otherwise be overlooked.
18. What lists are available? - Help get lists of what available in the community & what we can use.
19. Need more information where to access LOCAL places
20. Need more info to get ALL the community services Confusing
21. Need more information and have to go to different "systems" Really hard going to apply, what is out there? Is there an easy way
22. It gives our client security that they would get proper help when needed
23. General knowledge is missing.
24. Support within ALL communities are important and should be accessible to all.
25. IHSS is important for us to help him stay safe at home - medical for his medical services
26. Need provide opportunity to have life of their own with support beyond the immediate family
27. My child needs constant monitoring facilitated play/activity
28. Govt' services are more at risk
29. Assure help is offered support needed for my parent’s family
30. Insurance
31. Struggling w/ how to develop PCP with my son is in a wheelchair & cognitive ability of 4-5 & some behavior issues
32. simplify/make importance of community integration - important to families
33. Because if we have to go to the doctor, we need that or else die
34. to have/offer services
35. Insurance - it is the only insurance I have
36. The supports that can maintain his access to services and keep services and quality of services in place.
37. Well, I want people to help me, so I am not homeless & on living on the streets
   - I like that I can go to OPARC staff gives me correct information on things that important to me.
38. Medi-cal is important for most clients because it pays for much needed services to support them such as IHSS, doctor's appointments, medications, incontinence, supplies, etc.
39. SSI & Medical SSI is important because it's the only income & medical for the child to support himself/herself
40. Having general services can link consumers with service areas listed above
41. Participants should have access to resources that can help them live an independent life.
42. IHSS!!!! Comprehensive Assessment!!! I put this as most important to me because I became aware of this service & the eligibility, somewhat late for my son. I help families & have witnessed the disservice of LA County IHSS - they do not comply with their job description
43. Consumers need proper services for support.
44. Peace of mind.
45. Well insurance important
46. It touches all bases
47. Health care is important to me
48. Because it gets people to do stuff Gov themselves
49. Many families are unaware of services.
50. Medical
51. Need supports
52. Medical Doctors help
53. To ensure medication/are care
54. Community engagement is key to all other programs, services and general life happiness being positive and effective.
55. Volunteer work.
56. Access the community.
57. IHSS
58. Health insurance.
59. Health insurance.
60. Because this area specifically related to community supports is vitally important to the success of fully including individuals and access for individual with disabilities to ensure success with self determination.
61. I find the feeling of safety provided by those different services comforting and important.
62. I like to help people.
63. We clean the library and park at Alum Rock.
64. We clean the library and park at Alum Rock.
65. Accessing community support leads to better health and well-being also helps people become a vital part of the community.
66. My programs allow for my health and safety. I want to be safe.
67. Want to meet people and make friends.
68. Parents and family support makes me happy.
69. Better Medi-Cal for medical.
70. Healthcare system is too broken up and not coordinating.
71. Generic services are badly needed.
72. More info needed on IHSS
73. Healthcare
74. Because of the need in Alameda
75. I put this because for my condition
76. Some people need guidance and support especially on things that needs detailed information.
77. Without these supports, other areas would fall short
78. No idea of what is available
79. You need healthcare and health supports.
80. Because I have MediCal and Medicare through Kaiser.
81. Without these supports, other areas would fall short
82. There are an amazing number of resources out there that people are unfamiliar with. I believe the more families/community supports can be made aware of these, the better our community will get.
83. Families and service providers need to know the supports that are out there. It's also important to build positive relationships with the community support agencies
84. Community education is something I've heard can be so helpful
85. Because I have on IHSS, worker who helps with my home and cleaning. I have medical for my medi-care
86. Formal & informal are the most important to sustain the individual and be part of the community
87. I put this as most important to me because without supports & services from the community of different organizations it's not possible to sustain & survive & it will be difficult, hard, for people with intellectual/developmental disabilities & their families as well
88. health care services are vital in promoting & maintaining health
89. Medical: Because they need to go doctor for check-up
90. Low income, need financial supports.
91. Because medi-cal is very important when it comes to clients with...disabilities.
92. We need more DSPS volunteer activities
93. need to know these are services to go for help
94. Families need help learning & accessing process of obtaining generic supports. Sibling & family support group
95. These services allow disabled people to actively participate in their communities but can be very difficult to navigate
96. Because medical is important to me
97. For 2 reasons. I couldn't work and afford to pay someone to be with my child if I didn't have IHSS. My son takes so many prescriptions, that I could never afford if he didn't have MediCal.
98. These supports offer resources for other kinds of resources
99. Parents cannot do it all - it really takes a village
100. I think it's what people need in order to be successful in living independently.
101. I did a 12th grade quest on Medicare project
102. I receive services
103. IHSS and MediCal have been a lifesaver for us as I cannot work in order to take care of my son.
104. So our DB adults will have services.
105. programs for personal needs
106. I don't want to pay for my doctors’ visit's and my helpers help me.
107. I will be getting these services soon
108. People need supports in the community
109. it affects insurance (health) money benefit
110. Would like to know about how to get more hours of IHSS
111. There is a lot of miscommunication for the state in regard to IHSS, I have had social workers tell me that as a parent it is my responsibility to care for my child, which is true, but then why do these programs exist?
112. Because it provides you with information about IHSS, Medi-cal Medi-care
113. Super important
114. Without these serves medical care would be lacking.
115. the more support the more success a person has
116. if you can make the generic services work, you can use the community to help you with everything you need.
117. Services like this is what helps many low-income individuals receive service that they need.
118. I think people should volunteer more in their community, not live in a "me" world
119. Everyone deserves access to healthcare, no matter their socio-economic status
120. My need for Medi-Cal & IHSS/similar services
121. I like the activities
122. RESPECTFUL
123. Integration is essential for value & self-worth
124. Meaning improvement of what already exists
125. I don't know
126. Medical n/a
127. I think it's important for anyone to have medical coverage, and for people with disabilities, I think they should be top priority
128. Is important for them to be at their best to attend any program or in the community.
129. So everyone could have a place for information on services available
130. I currently work with seniors with disabilities. I want to learn how to better provide services.
131. Would like to have RC to support consumers in a community settings
132. Services are vital to all.
133. Supports - It is so hard being on the edge of services (income qualified)!
134. These effect our children the most for their services
135. Having an established support system for the entire household allows for the individuals to provide intentional services which support the individuals needs
136. my son's age at the present time
137. Families w/ kids/Adults w/ develop. disabilities greatly benefit from the community supports. Families have testified how grateful they are, and how more would be greatly appreciated.
138. Child needs to be healthy in order to be successful elsewhere.
139. I believe that once you receive information for your regional center it helps out tremendously, and exposes you to several different options, as well as making you feel like you are not alone in helping your child, help is out there.
140. The information today was really good.
To care for someone with developmental disabilities it really helps to have services like IHSS and Healthcare.

Medi-Care; Health Clinic

Because Health and community integration

you need financial support to complete goals

Highest form of support

Without support they wouldn't want to do everything else.

Because without all of these services our communities are not complete. Child Care, Early Intervention, Education, Employment, Health, Housing, Transportation. It should be the #1 in every human life and communities

Access to services

Keeping medicaid, medicare and SSI is critical for my daughter

So people with disabilities can get help and services

Need direct support to assist with all areas

Unable to find doctors, dentists, and mental health that will accept Fee for Service Medi-Cal.

Because my child lack of activities or programs accommodate his needs like swimming, outdoor activities (some are once a year)

Help with my money

Because of my health

Help pay for things you need.

we need collaboration with generic agencies so that our clients are well served.

services are needed for everyone who qualifies

We need mental health providers

Community supports help everyone

This is most important because without supports, people with disabilities would not be able to participate in society as prevalent to. This aides them in participating in society.

I like to keep organized and respect priorities

farming

clients depend on Medical insurance benefits

This is the most effective support thus far.
166. This is so important as Far Northern services as the hub of resources, services and information to people and their families to navigate their needs which enriches their lives.

167. Because it is the most basic element contributing to quality of life.

168. Education is first. My daughter's education is right now the most important thing

169. Because the finances help lead to #2, 3, 4, 5.. etc. It makes it possible to help support inclusion, education, employment supports

170. Stronger connections with local communities promote inclusiveness and opens more opportunities for partnerships.

171. My daughter is getting older and will be looking for stuff offered.

172. If I get hurt I can use my insurance

173. support of disabled adults

174. We don't understand our rights to services and we need help

175. more info on support services is needed for the community is needed - finding supports and getting the information to everyone. Lots of great resources available (or needed) and no one knows about them

176. Important to be able to function and be present

177. present in the community.

178. low wages threaten preserving these services that are the foundation of most services.

179. People are dependent on individuals and relationships in their own communities outside of standard R.C. funded.

180. It takes a village to care for the disabled

181. My adult child keeps losing their disability SSI benefits.

182. It is difficult to help others if we don't acknowledge that a lack of community supports is preventing them from being successful.

183. MediCal provider participation a big problem, also seemed to cover umbrella of psycho/social needs for inclusion

184. HCBS - people don't understand what it means and how to get there

185. Help with advocating for the parents with children with disabilities would help parents get the help needed to provide suitable environment for their child. It would so provide more information on resources available to parents.

186. Covers the cost services we use, IHSS and Medi-ca;
It is constantly changing and impossible to know all the resources available.

We need resources in rural areas to our native tribes are outlying regions.

It is important to know how to access these programs, which are very helpful for those who have a family member.

Because sometimes we need to know how to navigate the systems, in order to obtain the services.

I use these services

It all begins at this level all the other areas will fall in place.

More information on SSI and the Cal ABLE act is needed

I did not understand the service of IHSS, until my son was in his late teens, I was not aware of daycare services for him when he was younger (RC) I was not aware of personal assistant (RC)

People need to be more informed about the support services that are available.

Church can help with needs if we know about them

My sister needs help and I work full time so I don't have time.

I believe that the community programs need to be trained and bolstered to support individuals with dd like my child

Families of DD population need more services, support, choices because of the extra burden. When a child becomes an adult the family still provides most of the care.

Trouble with IHSS worker and getting PA hours from regional center

Parents need help to navigate all the agencies and put the services together for our kids

Most people want to do chores, but don't know how to do dishes etc. Don't learn it

because it is important

funding is paramount

Helps the community as a whole

I had to quit my job to be a caretaker

Because information on benefits is so important to families, whether they are formal or informal

families are often not aware that there is help available for them

Maintain these programs
Without community supports, the quality of life for people with disabilities and their families would greatly decrease.

My child has RC services and there is no oversight and accountability over this system.

Has allowed us to keep our daughter in our family home thus far.

It covers the basic as a whole.

So my daughter can live independently.

because there are too many disabled people living with advanced aged parents and if better supports were available, perhaps we could avoid needed to build lots of additional housing and support people where they already live, since their parents will eventually die.

Need more support for providers - not enough of them.

Health Insurance is important because many insurances are not affordable with disability monies, making it hard to survive.

Day programs in my area needed

Those systems are immensely complicated and bureaucratic.

everything is vital when you have a child with special needs but the support we get from the state is the most important because we need a lot of support and help financially

Language and cultural barriers continue to limit access to non-English speakers.

My child is 21 and finding these can be difficult.

Most applicable for 24 year old

My son lives in apartment with support services

need this to access many services

because we use these services

Respite and IHSS help us keep our child at home and survive it ourselves

To help family be well

Generic resources need to be easier to access

Lack in current system

Need more information on supports for our children

without community support , it would be hard for me to live on my own
233. It is almost impossible to get and keep reliable personal assistants (and constant change is harsh on the DD). Also many programs in CA have closed because of not being able to keep staff.

234. This is necessary to make all the other pieces work, such as housing and employment.

235. I don’t feel we can actually number these almost all are critical

236. Because without the informal and formal support nothing else works.

237. Need more community and volunteer activities.

238. Social security is important.

239. We do not have quality medical care for our clients

240. All info of disability is never given until later many times and we are informed late

241. Because most of the services that I receive are from the regional center or DOR and the DOR services I receive help me with my classes and regional center helps with my job coaching and if I ever need to get a new job, DOR can help me with that.

242. Community support Are important so persons with disabilities can have access and be included in the same services as everyone else.

243. I like to help people by volunteering

244. While I don't work with this population, it would seem having this broad support infrastructure in peace would help their family. Many other services and support they need,

245. IHSS pays supported living staff

246. People with disabilities will need HCBS compliant support to live inclusively in the community, and there are too many situations that don’t offer the choice that they advertise. We need to promote community living services.

247. I don't know.

248. Church, it helps me listen to scripture and the pastor. If we go out, I like to go to church.

249. Social Security check is important because it is all my money.

250. Go somewhere in the community.

251. For fun.

252. It's good here. (OPARC)

253. It's important not to be made to stay at home but to go out with everyone.

254. They help you out a lot.
255. I don't know
256. It's a part of community life.
257. People with disabilities need support from the community
258. A person with disabilities benefits hugely from community supports.
259. Public benefits is very hard to understand. Working with SSI, Medi-Cal, IHSS is very confusing and difficult.
260. The coverage standard seems to exclude developmental disabilities (ex: coverage hours for IHSS, are mainly geared toward physical disabilities and don't do a good job to address the developmental supports needed. Also we have a number of babies born exposed to drugs but lack appropriate mental/developmental health services.
261. There is a significant lack of choices and opportunities for quality activities if individuals require support. Ex. There are two day programs available, neither are very flexible or community based, one has a years long waiting list. If people don't happen to fit in one of those choices they are left behind and families shoulder the entire task of care.
262. Without this, the other services don't work out the same
263. Medical insurance and social security are important to me.
264. Because we go out every two weeks but I only get $10 every time. I need to get more money.
265. Need support for independent living.
266. The individual and family needs supports in all aspects. the person with disability should be included in the society not excluded.
267. Whether these services help addiction, mental health, early intervention, support, etc. It will help!
268. I need IHSS Supports.
269. client advocate
270. Lack of resources, need increased knowledge of what's offered in the community for DD population.
271. Clients need help to fill out forms and meet deadlines and help to provide copies of documents
272. Community Outreach
273. We have received a lot of support for our child with Down Syndrome and it has been so encouraging and useful!
274. Medical is a necessity
Often times these generic resources enable families to take care of their children and adult children who are not able to care for themselves, often their parents have to forgo employment; requiring SSI and IHSS to maintain income.

Support is always needed

Family are in need of all kinds of supports not a single one. Their need for accurate information is important for parents with children with special needs. Resources are critical for families.

These will offset some the burden on Regional Centers

People need to know what is out there to help

More community supports promotes inclusion. Access for people with disabilities is access for all.

many families are unaware of how many supports are in the community to access

I fear that Medi-Cal will be diminished greatly in future years and people with disabilities count on such supports.

These services not only lessen the financial burdens on caregivers but gives them the incentive to be a contributor to society.

I think moving away from paid supports and moving into supports that are not paid are the first step to a life of community

Many of our students won't be able to hold a typical job, so having other types of activities or volunteer opportunities to keep them active in the community is essential.

I like socializing with others

to have more friends

Working in the field, it is very evident that many families do not know how to navigate the system.

Because It is the most important that I have a good provider.

Because our kids need Medical to get the services they require ex Speech, OT, physical therapy etc. IHSS helps parents so that they can stay home and care for their child or have someone help care for their child.

Gives clients more exposure to community life

I have recently had surgery leaving me unable to walk. There are numerous parents out there that have to work. Because of this new loophole, "trial day", my son and I can't believe 80% plus persons served don't qualify for adult day care. Almost a moot point since southern California programs are
saturated leaving us on a nonexistent waiting list. I have been calling 2 in
my area for over a year now, about 1x a month, and they don't recognize
my name ever. Yes, I am talking to the same person just about every time

293. I wish that I was healthy.
294. These are critical services to stay strong and think clearly.
295. IHSS is what helps me to care for my son.
296. These services enable the functional quality of life benefits.
297. I can’t be everywhere for my child, it takes a village!
298. We need more support in the Coachella Valley area who are Spanish speaking.
299. Without community supports people can't live independently
300. Without IHSS I could not remain in my own home.
301. That is what self- determination is about. Life is lonely by yourself
302. laws, procedures are always changing
303. I still have not gotten medicaid or IHSS
304. It hits the needs hierarchy. IHSS allowed me to stop working and focus on the children and that has made the single biggest contribution to their progress elsewhere. If we aren't financially secure, everything else becomes secondary in our society.
305. Clients need creative services
306. Without support from the community, all other areas of concern won't matter
307. Without the support of the community all the other categories will not work as efficiently.
308. These services are difficult to access and navigate; in particular medical/health related services.
309. In order to start somewhere, resources are the #1 thing that is needed to begin looking for help.
310. Families requires a lot of support
311. Medical needs
312. Medical and IHSS have been hugely hopeful in our journey to provide our daughter Sadie the best quality of life. As a parent that has lived the "special needs life" for 10 years, I would also say that respite care to give parents a break is essential for their well being in addition to the needs of the kids.
313. STABLE INCOME RESOURCE
314. I have an adult child who had many services reduced due to her age.
315. we are losing more and more community services and our community is suffering because of it. Families depend on those services and then they are pulled
316. Many participants of families that I serve ask many questions regarding these community supports
317. Our population is still too isolated from the wider community
318. facilitate quality of life
319. IHSS has been important for my family and me. Medi-Cal has allowed me to obtain comprehensive medical care (now at my local hospital and clinic). Church activities have been important too.
320. It's important to have good health care to stay healthy. There are some people who don't have these services and are unable to get medication when they are sick. Also for any sort of services.
321. Because we need to be prepared, and changes on requirements to apply.
322. Important for me.
323. more services and insurance needed
324. need financial assistance
325. I addition to school, this is our primary focus now
326. social isolation is a major health issue for spectrum disorders
327. Because in parallel with special education our children have other Services such as IHSS, RCOC, SSI etc. and everything connects, shares and uses information on all systems
328. Need to find out what is going on in the community with self determination, etc.
329. Because it is what I use the most
330. My son like to be including in the community
331. Because medical and all programs are important.
332. Kitchen and Cafe
333. I lost $400 they didn't put in the paperwork
334. could use more support
335. Got help for the person with disabilities
336. people don't know all many things available
my patients receive authorization for therapists via these community supports

They need more support from community

I love the people & learn stories & songs friends

This can be confusing and difficult for families people served to access

These areas I notice a deficit in

Having a good support for clients eases quality of life and productivity

Volunteer activities to create a sense of belonging in the community

Make sure I get ILS support to pay bills - do dishes & chores

I would like others to know I'm very capable to do this with myself

for assistance with personal care and appointments

I love the people learning my story

Pathpoint gives me friends, community & purpose

we all need health care

volunteer activities - To have that work experience to get a paid job.

I think, it's very important for people w/ disabilities to get into the community

Because they tend to disappear being without big government.

This goes with education without support what they learn may not be possible.

Because I like to do things like go to church & go work.

community involvement is critical

To meet HCHB guidelines & requirements. Consumers need to see for themselves what is available in the community beyond the malls, parks and featured restaurants

Medi-care/medi-cal up to date is critical

Medi-cal, Medi care and IHSS are VERY important

Inclusion in community is essential but housing is important too as well as quality assurance.

Community will care for my child after I am dead.

Because we need it.

health care services

More day programs.
To know all resources available
Need health care for wife and I.
Early intervention
Increase from 2000-20,000.
Clients have long waitlists and access is sometimes not available in their areas.
Knowing the resources that we actually have as a community is important.
Health and well-being
We have trouble navigating the ton of paperwork before.
Learning games.
Volunteer activities.
Having community support is very important for families who need that extra help.
To make sure I have all the support that I need and support to be an active person in the community.
Helps pay for my doctor visits, volunteer helping community.
Healthcare is very important because we need a good and affordable health service.
To help people and make new friends.
Health insurance/medical support is a basic human need.
I like to support and be supported by the community.
Go out with friends and have fun.
Healthcare is important to me so we must advocate for our friends and participants.
Help me get education to pay bills.
Services (especially financial) allow opportunities that people with disabilities might have a hard time accessing otherwise due to inability to work, etc.
I see the need and change in the population.
The support currently "fill the gaps" in the service system, but they inadequately fill the gap.
Health care
This assists with the independence of individuals with disabilities.
In order to take control of people's lives, they have to be familiar with the benefits available to them.
390. Medi-Cal allows us to be healthy and receive services.
391. It's important to know the free resources available through the community medical care matters to keep families healthy
393. Healthcare important to stay healthy
394. Families can benefits from the services but do not know how to obtain them and making changes are how we help them educate the family on the agency and paper work in addition to the eligibility criteria
395. I think it's important that the elderly have Medicare and faith based activities to stay busy.
396. Giving back is very important to me.
397. We need support to help us with life, whatever area.
398. Leave the cost. Please.
399. Low contribution but full coverage.
400. Needed in the community.
401. Make sure that medical insurance is provided. It is important.
402. Medicare - Because I always bring my medicare to show it to the medical officials during my appointments
403. Because it helps me
404. Because everything is expensive too me.
405. Because I think it would be good for people to get out in the community.
406. Want to talk about work help.
407. Because I want access to high-quality care
408. Important to be part of a network
409. each person should join and enjoy their life, if there's this community support for the intellectual disability.
410. There should have more doctor and supplies
411. Living within a community that understands the importance of supporting each other should always be a top goal.
412. Because the Inland Regional Center and a certain supervisor and her dedicated employees have tried to continually take what we have received or used it against us or caused us unnecessarily financial hardship and even made false reports saying mom was bipolar and wanted my son removed all because I asked for vehicle modifications, was I wanting to start a therapeutic group home for kids like my son who would have benefited from it and I showed them the bus. Plan showing them that I could do it way
cheaper than they were claiming they were needing and as their letter to the conservative court investigator and APS reads that IRC is requesting my son be removed from mother’s care because we think she is bipolar due to the fact she started a website on face book called Inland regional center from a client’s perspective. I have the proof - call me for it 949-249-0629. So my theory is if nothing is done to stop Inland regional center, then it won’t be as valuable as inland regional center keeps encroaching on it. Particularly what we get from IHSS THAT SHOULD PAY OUR BILLS AND IR C(oops on the caps) has cost USA $70,000 truck expense for a bad modification because they forced and made decisions for their chosen vendor to make welds on the conversion against my permission and it just goes on . Also a denial on an already approved rental van that has now cost me almost 5,000. That truck was half paid for with my son’s trust - all of it and I make $600 a month payments on the rest to which IRC then paid $39 thousand for a now worthless truck that the roof is slowly caving in on. IRC won’t give my son any help and they write response letters that are filled with nonsense. Our lives are hell because of them. Mary Pounders, Monica Siegrest and the legal department. Also other CSC’s they have been through who did their dirty work at the controls of Mary. Don Meza was helpful until he turned things over to Mary.

413. Because we need better programs
414. My need to care for my son 24/7 take a huge hit financially, emotionally, physically and our family's well being
415. "health-insurance (medical/medicare)
416. workshops and different options for affordable health care"
417. Confusing to find good fits for each family
418. My sons needs a larger community
419. I don't think this process is easy for families so having a place to refer people to is help me
420. health insurance
421. This encompasses both physical & mental health support, vital for life long well being
422. parents who lack home resources or knowledge require extra support to complete and understand forms to submit properly
423. I don't know what to do first
424. Formal and informal is important to because your insured with these benefits that could cover your doctor, medical bills or/and cover medication. Volunteering is important too to gain experience for a job
425. Community integration is essential to success.

426. Social Security is constantly being cancelled. Medical is constantly being canceled. Brand name life saving meds get dropped. It’s a continual battle. What happens when we are gone. They can’t fight these battles. Someone will just find them dead and say, died from disabilities etc. Who will know?

427. IHSS is CRITICAL to allowing people to live among their families and supports.

428. IHSS - wages too low to attract stable & competent staff. It's a crisis for those who need intensive IHSS supports.

429. Being part of an inclusive community is important

430. IHHS and Medicaid need to be continually protected

431. Service Coordinators case loads are too high at regional centers, this must be addressed.

432. to help people

433. I want to be more independent

434. Expand IHSS to include more services. Community services

435. Regional Center is an important resource for our community

436. SInce my son is hard to find a job he needs some kind of support for living.

437. she goes to IHSS

438. to help out with financial help

439. A lot of families struggle to get the help they need do to funding. It would be best to get as much support

440. services are important - to get out in community

441. people are funny and help me.

442. Being supervised in case of injury

443. It offers help to those that are pro-active in the community and this better prepared to advocate funds

444. Families need to know the resources available b/c early intervention is so important in supporting children

445. it all needs to work in tandem

446. IHSS is very important to people who need it. Keeps children with disabilities at home

447. these service must work for folks or their lives fall apart
Because people need help. They need to know that there is somebody out there that has done this before. And a lot of times they need direction. They need to know what to do and how to do that. They need help hooking up with the programs they need. A lot of time they need help paying for those things.

Because these services help people w/ disabilities

Without Community support there is nothing to support other areas

IHSS Care Help

IHSS Care Help

Weed - you want to have fun

Important to connect/meet people through services.

would like to see people more involved in their communities, church and clubs

Medical is very important because most of the disable's parents can not work and afford a health insurance (because they are taking care of the child)

In addition to education, community support makes a difference

It's important that IHSS and medical receive adequate funding for nursing and care. IHSS workers do not get paid much it's hard to find reliable responsible workers

Health is important

We need community support

I will always need support to survive where I live on my own.

My insurance helps me not worry about my need of my health

These services helps provide safety security and start to independence.

Again, contributes to better, healthier communities

a reason not given

having the right support allows freedom for the recipient and caregivers

MediCal for Homeless

Because I believe that IHSS & Medical needs more understanding on how the qualify applicants

To ensure adequate health care, and daily living needs and skills

Lack of services/supports that are consistent & meet needs. Lots of unmet needs go unaddressed.
In case something happens to us he will have services that will help take care of him.

Important to know what services are available for my child

Support is always needed

It is important for the developmentally disabled need help with paying for their services and need support as well as their families

Of getting more support for the community.

I need help filling out forms and stuff

Without the community our kids can't get what they need. I feel like the community would like to help but they don't know how.

Due to the disabilities, they can not take good care of their own health and need support even for daily living.

Home is the most important place where they spend time. Home should be safe, comfortable, and enjoyable. Home is also the place where they are learning many different areas of daily living skills and functional skills.

We need more incentives for people to become community support partners. Pay is ridiculous and does not reflect an attitude that says, "our DD population is worth supporting"

Ensure that the community can sustain services of people who are under educated

services for community are important

we need quality mental health supports

Without medical insurance it is difficult to pay for services.

We need to know how to plan for the future.

Someone needs to be involved to let everyone know what is out there.

Independent Living Services help me go to the store.

They help with my needs without being expensive

Inclusion is to housing, jobs, recreation etc. Inclusion requires support to be effective.

I need insurance to stay healthy

Help get services when sick

Important to help take care

Need medical and IED information

we need crisis centers for our regional center clients
495. We need counseling for children of Jr. High School age who have Autism. Very much needed.
496. We need increased provider supports and education for transition aged students.
497. All parts of our service system need enough money to live. Service coordinator caseloads are too high to be effective.
498. Everyone working in this system needs to make a living wage. We cannot have stability without this occurring.
499. The community supports are important to help support.
500. Services are important to me.
501. Too many services are cut rather than funded.
502. Without community services our members would suffer.
503. Because if you get sick or accident or hurt you need see a doctor.
504. So that I can thrive in my community and life.
505. I depend on Medi-Cal for services for my son.
506. Many of the individuals we serve are having a hard time finding programs they can attend because they are full, or programs cannot meet their needs. Especially those with behaviors. A daily outing is really great for individuals who otherwise would be home 24/7.
507. There still seems to be much disconnect between service systems working together.
508. Community resources such as mental health treatment for the developmentally disabled population is an area of great need.
509. Medical.
510. Our community needs to provide for our clients so they feel a part of the community.
511. Provide more Psychiatric services.
512. Generic services like IHSS, SSI. Expand funding so people can be part of their community.
513. We are not told about all services.
514. Finding medical and dental services has gotten better, but this should always be a concern since the changeover in the CHC system prevents continuity of care.
515. It’s very important to take care of our special needs, such as medical.
516. We need help with our sons and daughters they can be very taxing at times.
these supports can work toward 1, especially informal

Thinks everyone should be active

Always have questions about social security for my family.

to have medical services when needed.

Everyone wants the option to make choices and having that opportunity is important. The choices of where, when, and who they do things with.

Need affordable health care

Want more information on DOR, workability and ways to help our adults gain or keep employment.

Because caregivers do not know how to navigate these systems to help their local ones who are qualified/disabled.

Health Coverage is a necessity!

It's important to be social and gather with other people whom have learning disabilities.

Community should be aware and support consumers, Manteca does a good job of supporting consumers in volunteering activities more needs to be done

The community is the place where we learn how to care for our disabilities correctly

Communities would benefit from group social programs

With the exception of individuals who are total independent, others will need supports to have a life outside of home.

WE HAVE ZERO

Because all people with disabilities have a right to access their communities and get the supports they need

Community support is important for the disabled to have access to all resources, acceptance and respected.

Consumers lack supports in many areas; mainly because they are not aware of the availability to receive such services.

This ties into the Health and wellbeing to me, If you cannot get the supports that you need then in trying to patchwork what you need as a support you start failing in what you love and what actually can help you while you are working.

We need to address the rates paid to our service providers. Programs are closing and others are not taking new clients because they cannot attract staff.
The Spanish community needs to be exposed to information if it is to have any support.

Because health is important to me.

Because thanks to that you can see a great deal in your children and you can help.

The services.

My son would like to be seen as a man, as opposed to a man with disabilities.

This will help my son to be integrated, included in the local communities and get to know people and do volunteer work.

So client becomes more productive in community.

Recreational.

because it helps with my health care.

for more supports in house.

Support is necessary.

Educate the community and get them involved about our population.

Getting community support is important for individuals in order to meet their needs.

making friends.

community supports I have medical.

Regional Centers need more help to serve clients.

more help for regional center consumers.

People are suffering in silent they need support.

Community is a big part of our lives, educate our children about different disability, and teach them kindness, we are all different.

I do need assistance with some things and making connections is always important.

Max inclusion, independence and community integration.

IHSS/Medical pays too low and could hardly get by.

more opportunity for more programs.

It's how families can learn about services and programs.

developing more supports for families with high need kids to keep them in their homes.

Need higher wages for caregivers.
Community supports help me have a more independent life.

It's important to have knowledge of generic resources available to the community at large.

Some Medical services are not available to patients who require sedation to stay still i.e. EEG studies for seizure patients; also, all care staff should be legally able to perform the same medical tasks (IHSS staff can do many medical tasks that personal attendants cannot)

It is important that our children have access to these services it is important to be able to take our children to therapy / help

We need all the support we can get.

people need access to supports in their community

Keeping in mind our dual diagnoses ID/mental health folk there is not a lot of cooperation between the generic resources/ county mental health and the regional centers. Everyone seems to think the regional centers are supposed to cover all services but they have a mandate to use generic resources first. County mental health has little understanding of how to work with this population.

Need for health services

Health care is most important

I feel that Medical and similar companies should be government funded.

IHSS and Medical for my child had been a blessing in helping my child live in his home and get the health care he needs.

Prevent isolation. Having disabilities is isolating enough

we need to be more informed of programs , etc.

parents can not do it alone; they are truly the only advocate for their child and need other players involved

Supports her lifestyle

Cause benefits are imported.

Federal and state budgets are constantly overextended and frequently supports for people with disabilities are under attack to be cut or significantly decreased. The population of people with disabilities continues to grow as a result of an aging population, the opioid crisis, under addressed mental health issues, etc. People with disabilities who could have the knowledge, time, energy, finances and ability to advocate, lobby or
otherwise organize concerted efforts in these matters are rare. Agencies must take on responsibility for representing their voice.

581. Provides financial insurance

582. they need work and help socializing and work

583. It's really hard to figure out MediCal, Care, IHSS, DentiCal, SSDI and conservatorship

584. It is important to work on social skills. Such as dances, bingo, community clean-up. Community gardens, etc. It lets the community interact with our Family members as real people and not just people with disabilities.

585. Because all disabled people need these supports.

586. Because can help the family know what’s going to be the right service for the kids to have support.

587. The more people are aware of and committed to a person the better quality of life they can have. I would love to see the focus be on more natural supports and community opportunities than just agency services. The goal should always be to have someone be a regular part of the community with friendships, relationships and alliances that insures people are well supported with a network of people thus avoiding isolation and abuse.

588. IHSS is our only option for care for our daughter.

589. seems like regional center in not involve as they were at one time.....services not being provided

590. Provide parents with information available in community

591. Know other programs that are out there for our son

592. Generic supports sometimes don't work at all or cancel each other out. Regional Center only cares if you might be able to get some financial support somewhere else. Whether or not you can actually get that support and all the costs and difficulties involved, is not their concern. It makes for nice paperwork and not necessarily outcomes.

593. The way the system is at the moment, it's changing to fast and federal laws require us to do things for the clients that we cannot do because non-support from them, we need more communities to pull together and get this "gap" under control so that when clients go into the community, they will be met with support and guidance as well as perhaps knowledge from their community.

594. Health care is needed

595. I care can be a lot for families so it’s important to get help from outside organizations
596. few available at this time
597. access to decreasing medical and dental services for our clients
598. Without healthcare insurance people are in mortal and financial jeopardy. They can’t get help for physical and mental healthy and they and/or they may need to file bankruptcy or spend food money on medications.
599. These are vital to a good quality of life!
600. Medical and IHSS are needed supports for families of children with disabilities
601. I know why, because I need more money.
602. We need better medical care.
603. We need much better funding for services.
604. Our services are of a very poor quality, we need more and better quality
605. People need more than the current level of SSI to live. Current rate puts people in severe poverty.
606. People you serve probably make around 12,000 a year
607. As Regional Centers are the payers of last resort, RC's and families depend on Community Supports for services. Navigating these services (IHSS, SSI) is a challenge.
608. People need affordable and accessible places to live
609. Insurance coverage is vital to consumers with DD/ID
610. Need to build on strength of community, govt regional centers can't do everything.
611. IHSS lets me be able to make my kid my priority medical helps us co pays.
612. We need more behavioral, respite and social recreation services
613. I don't know.
614. IHSS is critical to family staying afloat
615. Access for DD persons in senior programs
616. They need support to survive in the community
617. I want my daughter to always have health insurance - Medi-Cal
618. Services through the state allow us to provide optimal care to our daughter.
619. Community involvement is crucial to the success of our community
620. Provide a safe and supporting environment for the disabled
I have too many graduating seniors that I have worked for four years (diploma track) and I have no real connections to give them to help them on their needs next step to adulthood.

These are needed to support health and well-being.

Broad range of assistance.

We need community support and acceptance

Because the current rate for community integration supports are inadequate to provide the quality of care necessary

more supports at local schools, or the school which primarily service I/DD students.

programs are important for training.

Ties in most to health and wellness.

it is important for people to know they are a part of the community and that they can help others and be helpful.

As relates to above: service navigation for oral and other health services.

I would like to keep volunteering for the DD Council

some rely heavily on their IHSS worker to help them navigate life. To me its important to have strong community supports

Trained providers need to help other support systems understand effective ways to relate to individuals with ASD.

It's my own information, you can't tell no one about your information.

Because I need social security to get money and buy clothes.

I need 24 hour support throughout my day

The current services that are provided need to complement each other and be flexible enough to provide the recognized and appropriate services for DD adults. If there are loopholes/issues in this actually occurring, then this needs to be solved.

IHSS is very important.

Increase incentive to have more pediatricians at healthcare.

To improve the community’s perspective on adults with disabilities.

too few social opportunities for disabled adults

Real life meaningful services are lacking. It is a fight to get needed service for individuals to the point that it is a joke.

We all need supports to lead a healthy life!
Organizations such as Special Olympics, Warmline and FEAT offer amazing services to families without bureaucracy. As the laws exist, parents have to become fluent with the laws and IEPs in order to become good advocates for their children due to the level of bureaucracy and the design of the laws. Too many standard public schools try to use the complexity to their advantage and provide only the minimum supports that the law requires. Unless parents are highly informed and educated about the laws, they do not know how much their child/student may be lacking with educational supports.

his health is a priority

Health care is needed, people are still shut out

The community needs to be better informed to know resources available to them.

Navigating the insurance system

Formal and Informal Supports

It creates safety

outreach to individuals and services providers

I believe there continues to be stigmas on supporting people with IDD and the community needs education in this area

More communities supports and help

Community is key in support. Knowing all key players for the individual can open up support that no one in the paid services had accounted for.

People living in their own home needs to have support to sustain independent living and reduce residential settings

There are so many generic services to navigate, its complicated and there is poor oversight and accountability to make sure these agencies are providing what they are supposed to

Because it helps me to get out and play with friends and meet new people like teammates and it's fun to play sports.

Support is necessary for individuals to be successful in the community

Often times parents express not being sure what community supports they have at their disposal or how to gain access to these supports.

activities helping, depending on needs due to their disability.

More education of how to access services in the community.

Without supports many of the DD community will not be able to succeed.
there is a lot of clients who are isolated because there is a lack of activities for them. Because it helps people with disabilities to have the life that they want and also foster relationships that are not with paid staff. Need help to know what is out there. Need more supports in the community. Spiritual Supports. More pathways need to be clarified for volunteers to help with patient care. Difficulty in finding IHSS workers impacts quality of life for consumers. The shortage of caregivers is at crisis levels and will only get worse as aging baby boomers will need more caregivers and can private pay. We need a national and statewide fix to address this crisis- more Medicaid dollars and general fund in combination with city and county funds for higher cost of living areas. Caregivers are not receiving a sustainable living wage. Students leave school and lose their safety net. They need more extensive transition assistance. IHSS. Inclusion in activities. again goes to safe community living. Families and persons served need more community supports. There is a huge Lack of knowledge of service agencies like IHSS, Regional Centers, Self Determination, Social Determination, and the Lanterman Act in our community. Clients need assistance entering new social situations, places for them to enjoy and participate. many would not have access to affordable healthcare w/o it. Circle of friends in his community. Ways to better integrate in his neighborhood. His adult program provides him with peer support and good care from the staff. Services are important. If you have a good quality of life. Transportation. Integration with community an access to its resources expands one's ability to meet currently unmet needs.
684. Generic services because it is the first point of help.
685. We have little support here in South Lake Tahoe. We have one lame day program that meets a few needs, but the other adults here are languishing at home or limping along with unfulfilled lives...Our other support agency has gone through a change of directorship and it inherited deep debts that need to be paid. Can you help; get this agency back on track with some financial help? They can't grow without becoming solvent. They need a clean slate to meet the needs of all the clients waiting for them.
686. for clients to be fully taken care of.
687. Supports allow people to live the life they want in their community
688. Community awareness will improve acceptance and respect towards differences
689. this is what allows people to live independently successfully
690. I feel that people with disabilities need as much support as we can give them.
691. Because it is most important to learn hands on with someone with a disability to get a realistic feel of what it's like.
692. Provide care for those that need it.
693. Because I am the caregiver of an adult child that cannot function at all and i'm not getting any help and I'm getting old and am stressed.
694. Adults with disabilities want and need socialization opportunities
695. Support services for clients/families that need it to improve functioning/wellbeing
696. Because I believe in the importance of social support as protective.
697. The support groups out there we need more.
698. Many families are getting wrong IHSS hours assigned.
699. Support and information of any kind is essential to families navigating through the disability community. There is so much we don't know and in order for everything else to fall in place, knowledge and support must come first.
700. Kids on the spectrum mature up slower. It takes additional time to be trained for a job. I have been trying to get SSI for my son for a year. It's obvious that they are trying to get me to give up. I don't need him to be on it forever.....just for now
701. Job support
having medical and IHSS, services to my daughter has worked out for her. Home day program working with a one on one aid has benefit her in self-esteem, also to live life her way with choices.

There have to be opportunities in the community to reach out for emotional support as well as opportunities for our youth.

Without these, doctor visits etc. may not be possible and health may suffer.

I think it is important to know how to take care of a baby or child.

Make friends in program

To make friends in program

To make friends in program

I am happy with IHSS services

To make friends.

Immigration needs a place to stop to ask question in their own believe and trust to keep them self confident in life.

Community supports are needed

IHSS so the individual who takes care of his/her family will be financially comfortable

Most issues are systems issues, need to ensure/advocate for all agencies to provide supports

For health safety

Consumers depend on their health insurance and can become vulnerable and at risk if MediCal is discontinued

More information on social media, internet security, social skills, different items.

Formal and informal community support is important because individuals with disabilities need support services to be successful with their lives

Additional services to provide care and support

Have more money to help support the grassroot organizations that understand our needs

Our clients depend on these services to survive

It is important to me because letting the families know about these resources can help those families in need -

No family or child with disability should live in fear of not being medically covered by insurance. Obtaining insurance should be low barrier.

Clients need assistance with ADLs
helps adults with special needs become independent and get help with lifestyle decisions

need better ILS/SLS wages to reduce constant turnover

to be independent to ride bus and Bay Area Rapid Transit

Although many such supports already exist, I have often had trouble identifying and accessing them. I often learn about supports that would have been available had I known to ask for them only after I needed them, when something has gone wrong, and someone asks me why I didn't do, request, or sign up for something that might have prevented what went wrong. Even when I do know something is available, I can't always access it. I found MediCal impossible to navigate and utilize, to the extent that it prevented me from obtaining necessary medical treatment. I've also been turned away from generic services because it's not immediately apparent that I may actually need them, or conversely because they assume I'll need more support than I actually do. I have even been told by a disability organization that they don't deal with adults with developmental disabilities (this was the only category of disability they excluded - they advocate for children and adults with any other type of disability, and children with developmental disabilities, just not adults with developmental disabilities).

with HCBS. need to find local integrated supports

Needed to keep up with their health

Needed for their health and well being as well as precaution from any illness

I'm a parent of a child with a typical child I will need supports to assist with acceptance and respect of all differences

Advisement of how to ACCESS GENERIC TO SAVE MONIES FOR CLIENTS/FAMILIES

More community help is needed

It is important for me to get supports to help providing housing placement and information.

This is very important because it caters all their medical needs and everyday vitamins

Insurance security

Services are important especially those coming from the government to make sure people with disabilities are also getting their basic needs met

This is very important because it others all their medical needs everyday vitamins

not sure
741. Access!
742. Supporting our love one, to make sure he have everything he needs to live a healthy and safe environment. Free medical for our love one
743. Health care costs are OUTRAGEOUS! w/o the Inst. deeming/waiver we'd be in financial ruin
744. I like to have fun!
745. people need support from their community when people feel like they are not alone, the can get through difficult times
746. Focus on health - make sure people have health care
747. Mostly because without Medi-Care or Medi-Cal it is nearly impossible for developmentally disabled people with no family support to get medical care.
748. I have help when I need it
749. It is important to have choices and support while in the community
750. Church, Pathpoint, regular social events in interest is how create friends and community
751. Because everyone’ health is important
752. increase clients need support with community supports offered
753. Need for "meaningful activity" i.e., job or volunteer that promotes growth and confidence.
754. In-home services - family environment
755. The disabled need to be involved in the community.
756. individuals with disabilities need community support! medical is so important for health also faith-based options for those involved in churches
757. To ensure health and well being our individuals need community support to get certain resources
758. I would like to provide resources for clients’ parents
759. It is important to identify these supports for sustainability
760. To address Health/Wellness
761. Medical and medicare is so important for health/ preventative care.
762. I feel as though it’s important for participants to have safe places & support to turn to
763. Make sure I'm doing well, going to see doctors.
It is important that clients are integrated into the community. For clients to live independent lives they need services such as IHSS to come to them, especially in SLS.

Training for all coaches in recreational parks.

All consumers need this a lot.

Quality of life and community-building is important because this are the services I received at home and at the doctor.

Because it's important to get the support that you need it.

Resources and assistance to get these services if clients don't have caregivers to help them. Activities help them be social, feel included.

Eating the right foods.

Again, families not knowing the health care info that is out there.

I am concerned about keeping the services my daughter has and gaining more.

So we have options for medical services.

going out.

I like spending time with friends.

Important.

So I can get good healthcare.

Having extra community support allows far more involvement or funding.

Creating balance, involving more people in individuals like creative social support/circle of support for the individual through those services.

These are the supports I need to live independently.

For health.

They support my first to choices.

So people can help each other.

Improve quality of life.

I work with adults with mental disabilities I've seen companies just hire anyone. sometimes staff is not good match with clients.

Government assistance is very important for people who can't work.

To complement all other support for the individual for a wholesome experience.

Navigating these systems is hard.
Important to know for support

I put formal and informal medical, because it is important to me that everyone have health insurance.

Support for those who need access to services.

Community support is needed to help with the above choices

Supports are needed for all aspects of clients’ lives.

It's important for people to know what is available to them

For services to be more accessible, more outreach, more training, more contract can broaden our clients’ recourses

Because these services are important.

I need my Medi-Cal/Medicare.

Social activities, transportation.

"Community support. the public needs someone from these agencies to help families and persons with disabilities have access to services.

" People need help because they are older and alone.

Just in case the disability is more severe that the client cannot have a job/work they will have equal medical benefits so that they may have a better quality of life.

Need medical/medicare and other healthy related support

Community needs to help others.

Support seniors who are sometimes ignored.

We need to know about HHS, medical, medicare, faith based and volunteer.

More awareness programs in the community to help qualify for services.

Need to stay healthy.

Having proper medicare can go a long way in giving those with disabilities the support they need to get by.

I feel safe in the community

Having more support can make the job easier and allow us better necessities for both staff and clients

Formal and informal community supports is my 3rd choice because I think everyone deserves medical and medicare, going volunteering events.

Hard to have on my own

Good way to help with social skills
because we all need the help

We parents do a better job without children if we have the support of these government agencies.

Social.

People w/ DD should have more competitive employment opportunities.

This gives people self-confidence and to develop a support system.

Once again focusing on when I can no longer care for my daughter and there will be more reliance on agencies to ensure the appropriate care is provided to ensure she is safe, happy and living a productive life.

Because without access to community support and services families fail to thrive.

These are all supplemental resources that our children need to access

Formal/Informal Community Supports are critical for individuals with intellectual and developmental disabilities to continue to thrive

many disabled need help to find activities to get them out of their homes and to better find some enjoyment in life.

There are not nearly enough programs outside of school that would include children in SPED and inclusion is not taught at all

it is that's why.

Community is after housing

More community groups or supports that serve more than just urban areas. Encourage municipalities to at minimum list accessible recreation facilities and programs.

Support for my child is so important.

There are more ways to help those in our community. Those ideas can be heard and eventually funded for.

I need help signing her up for all that is available

just in case they take it a way you can get a new one

IHSS: Some children are extremely difficult to care for and without this service we would be homeless.

IHSS needs more funding. Caregivers are required to provide 24 hour protective supervision and only get paid for half of it if they are lucky. Sleepwalking and aggression when he wakes up are real threats in our home. I have to protect myself and my other son even when I am supposed to be sleeping.
836. For the same as above
837. Trainings, cross collaborations w/ agencies, hosting days where several supports are gathered in one location in order to help families sign-up and receive services.
838. I would like to stay healthy and happy to have quality of life
839. health is important and activities to volunteer in the community is a great thing
840. I think it's important for somebody with disabilities to go out in the community.
841. It is important to have other services to help from
842. I want to meet new people.
843. awareness
844. because then we wouldn't have health insurance
845. Volunteer. Get ME REAdy FOR WORK
846. This service allows individuals to get the supports needed to be health and gain skills to become more independent.
847. My daughter will still need IHSS support and I would like to see what volunteer opportunities might be available for her
848. Organizations that offer help are important to me.
849. Those with disabilities won’t always have reliable relatives/friends willing to help
850. Communities help connect people and gain skills
851. HELP PEOPLE ENJOY RICHNESS OF COMMUNITY LIFE & ACCESS SERVICES THAT CAN SUPPORT COMMUNITY LIFE
852. many under-privileged communities can benefit from this
853. sometimes I need extra service in order to learn to be self-sufficient
854. More support from Public agencies.
855. IHSS, Police, social services all need to work together
856. all systems must work together to truly help a person, child or family
857. all systems need to work together
858. lots of challenges in making systems work
859. Health care is needed to address physical and mental health needs.
860. Provides support to those that may not get it
861. provides the support I need
862. more conversation groups in order to tell people what I want and need.
863. we can work together
864. As a person who provides these services clients I have served won't have the quality of life as they do with
865. People don't know what is available to assist them
866. IHSS helps keep clients with their families, which is wonderful for them. Health insurance is vital.
867. People with disabilities need support I consider it a very important issue.
868. Programs, online access to list of agencies that can assist at all ages not just 0-3 or adult. Again families need additional supports proper to navigate the systems. Assessment/placement
869. we need a wide range of services that are welcoming
870. Because I have MediCal and I want to commit to health
871. I want to keep my program because it is important to me to be happy and have friends
872. Community Supports is important so I keep my program.
873. It’s important to have insurance to take care of yourself get help emotionally, physically, mentally, Dentist etc.
874. We need more support agencies who can help find adults with disabilities employment and that can support supportive living services.
875. All key elements in maintaining satisfaction on and off the job
876. a reason not given
877. to raise my special son requires much community support
878. because this unites a community and helps people who really need help and will develop meaningful relationships
879. Individuals require support from community professionals to ensure healthy, safe environments
880. It is important for my child to have services as Regional Center
881. It is important that he has access to health services and support services so he can keep up on #1
882. These services support the family as well and the child as we work toward her independence
883. I live off SSI & SSDI, it's how I pay my bills.
884. Social clubs/groups counseling/therapy
885. Our family would not be able to survive if it weren't for the supports my son receives, IHSS, Medi-cal, etc.

886. We need more service coordinators at regional centers, caseloads are very high.

887. Supports creating more services that can be diversified to meet the needs of people in the community.

888. These are all programs that are needed for all and will help them to get to better health and healing.

889. Having different outlets for clients to have access to and having it become buildable for each individual client lifestyle makes job opportunities for staff and future staff more available.

890. People with disabilities require multiple services.

891. Clients need all forms of support in their lives to help them become successful.

892. It takes a community to support a disabled or handicapped person so they feel they have support. Getting into supportive environments like being involved in a church or club can help.

893. Help accessing services.

894. I/he need help with everything.

895. HHS has been no help in providing services for my family to obtain proper health care.

896. Reduce regional center caseloads by increasing the allocation for service coordinators.

897. Families need support in the community.

898. Someone should help. I just get I'm sorry from the Regional Center. They can't do anything.

899. The more exposure our children have in real community experiences and jobs, volunteering or paid, the better they feel about themselves, the more positive they identify with their peers and the community.

900. Health.

901. We need to have the regional center funding addressed for service coordination, the caseloads are too high to serve the community in a professional manner. Also the rate study needs to be implemented to improve the quality of staff that work directly with our clients in the community.

902. Regional center caseloads are too high!
regional centers need help so they can provide the service people expect and deserve.

Very important services like IHSS supports helps us

Community supports contribute greatly to greater self Determination, better health and quality of life.

Expanding the range of options would be helpful

WACTHING MOVIE

This was selected third because it was necessary to rate only one at a level. However, individuals without the appropriate supports whether form or informal will not be able to function in our society.

Accessing paid and unpaid support is essential to quality of life and community inclusion and acceptance

medical insurance

job skills

jobs

Good way to get to hard to reach communities

Help keep my sight to live healthy

These community supports are vital to the continued success/longevity of the efforts of persons with disabilities and their families

In home supports are necessary for quality of life

It’s fun

Families and individuals need as much support as possible

Because I've been on medical all my life

It is important for people to have supports available to them.

Helps with life choices

Community awareness outreach

we need to address the direct care crisis here and in the nation. We do not have the staff we need.

Parents are limited in finances due to the amount of time spent on medical appointments for our children. It makes it difficult to work due to absences. So it is vital that financially these programs stay in place.
Community supports are important in that it gives the opportunity for all to achieve buy-in in the nurture, support and collegiality with the developmentally disabled population. Community supports allows all to grow together as we get to expand our knowledge of each other more.

We could all use more supports.

Medical health and access should be important to everyone. Care homes need to be held accountable or health and making sure consumers are receiving the best possible care. Too often are consumers sent to programs sick.

It's important.

This population needs social activities on weekends.

Most services already exist in the community, but are not accessed because lack of resource sharing and information on those services.

Apps are long, how can we help.

There is not enough community support for disabilities, especially for children.

Important for both individual and their families to be supported.

Hard to get good doctors.

Medical is important to me due to out of pocket expense being so high.

I see tons of activities for mainstream children and parents. I would like to see more with helping develop social skills with play, engagement, interaction classes, camps, sports.

IHSS, some children are extremely difficult to acre for and without this service a lot of us would be homeless.

The general public needs to be more aware and able to understand what helps them.

So that they can take us places.

People with disabilities need support with accessing the community regularly and building lives just like everyone else.

I see this as an option for increasing access to #1 and #2.

Support services are how clients obtain and maintain quality of life.

People don't have access or info about what's already available.

Without support we are shut off from our communities.
connections allow networks to development. The systems in place aren't adequate to meet needs. Community development may provide flexible informal support

Formal community support in regard to having more opportunities for our adult children with developmental disabilities, to attend a class at a community college that involves more than just an adaptive PE course. Possibly art appreciation, drama or music.

Community development may provide flexible informal support

Formal community support in regard to having more opportunities for our adult children with developmental disabilities, to attend a class at a community college that involves more than just an adaptive PE course. Possibly art appreciation, drama or music.

Counseling and activities crucial

We need more opportunities for children to learn society and the ways of life

families sometimes feel they are all alone and don't feel they can relate to others, community support is vital

People need supports to live on their own

the caseloads for regional center service coordinators are too high for them to do their jobs,

service coordinator caseloads are too high,

I need information about the Medi-cal that I charge and what services it can get.

Interested in more information about these terms

I would like to know how to learn about IHSS.

supports for behavioral health, people cannot get help they need

Our service providers need rates that are high enough for them to hire good people who will stay longer than a month or two. Also caseloads for regional center service coordinators must be lowered for any hope of good case management to be delivered.

These services support healthy growth and skill development

creating more social opportunities for my son would help his quality of life

make regional center eligibility broader so we can serve people with mental illness

IHSS is important, people do not get paid enough

important for a good community, health is important

the community's supports are very important to people with disabilities

buddy break and respite programs for young adults with support for individuals with behavior challenges are important

Needing extra supports

Knowledge/awareness of community supports/resources.
Without these it is impossible for individuals to live independently or to not need a full time family member to assist. Community offers a lot of resources so that they have some options what they want to do. In order to do all these things (socializing, working, school) people with disabilities need support to reach their goals. Allow for more flexible services and trainings for service providers. Not all of these types of services are available to the I/DD population, such as mental health. Lack of services in this rural area. Services are important to continue respite care because it is very important. IHSS is extremely important. We need to value volunteer and give back to community. All of these supports are important. For people with DD to live in the community and mature away from their aging families, we must provide maximum support for them to be safe and stay active and stimulated, not served in a minimal way. These are vital supports that make life possible. Being part of the community not isolated with disabled peers and caregivers who are not motivated to engage clients. This is critical and hard to navigate, note this category is broad. People with disabilities are increasingly being killed or injured because law enforcement aren't properly trained. I think many families with disabilities don't know enough about services available. These are required for an individual with disabilities to live sustainably. Improve quality of life for both people with disabilities and those who do not identify as having a disability. Community support as IHSS and Medi-Cal are extremely important for people to stay healthy and to be cared. Again, we need more agencies or the ones existing to directly assist persons served and/or their families with filling applications, advocating on their behalf, talking convincing the private sector to embrace and invest more in our population.
These programs are key to helping those with developmental issues.

These supports are fundamental in supporting the individual and their families best support someone with disabilities who needs additional supports to succeed.

Because it takes a village, but we didn't know what's available to access.

SLS Services, IHSS services relative to physical and mobility impairment.

We weren't ever able to find a support system that worked for us. When we did, Ohr Lanu (family camp at Camp Ramah) weren't able to get the word out to others who might benefit. Also it took MANY hours to find what local camps had programs.

Because he should have a full and meaningful life.

supports for education and employment and all

Our son desperately needs adult day supports that can handle his complex needs, including aggression and property destruction.

church. I like going to church. It's fun.

I would like to have more things after program

Medi-Cal is important to have insurance

Integration into a community has value.

IHSS/MediCal - IHSS help me stay in my own home with family.

Because the family needs support and information to navigate services and their journey

The community needs to know this child's needs especial care

IHSS. Is important to me (even though we do not receive it), because families like mine are struggling to care every second of every day to care for our loved one way more than a typical family could ever understand. A caregiver cannot maintain meaningful employment with a special needs child like mine who has self injurious behavior.

Have a police officer come and talk to our kids about being out in public and possible interactions with the PD Have ID ready, tell the officer you are Autistic, etc.

He has special needs that are benefited by Resources like New Horizons

Participating in community and activities

Medi-Cal is so low funded that providers don’t want to accept it. IHSS needs to be more giving rather than stingy of support hours.
1010. People with special needs need to be out and seen in the community. There should be a safe and supportive place/community.

1011. Assisting self-advocates and family advocates to recognize that they are making life choices for whatever services are required

1012. We need Formal and Informal Community Supports, constantly!

1013. She needs inclusion to the community, to be able to learn to communicate and socialize I. A positive manner. streaming

1014. I would like to see one agency that has a complete list of who can help. Most of the time you only hear of support when you are at the end of your ropes.

1015. I feel like I have to search for these supports.

1016. health care is not always the best, need help to get care

1017. Supports such as these provide a bridge between parental/caregiver support and individual independence.

1018. Community support is import because the individual should feel included in community. There also needs to be community awareness.

1019. IHSS is a mess not even paying minimum wage. It can take 6 to 8 months to get a new person in the system

1020. To include disable people in the community

1021. All individuals with Intellectual disabilities need supports from either family members or community, I would like these services to be available and friendly

1022. Supports are needed for community inclusion as opposed to segregation.

1023. Children receiving code 116 services would benefit from group social speech therapy programs.

1024. finding employers

1025. These are services that people with developmental disabilities have a right to access

1026. the supports of mental health and basic health care are not available

1027. Mental Health Services are not available

1028. It is important especially in rural areas that all services work together to maximize outcomes for individuals.

1029. community supports and services
1030. After having housing and being physically safe, then receiving support is the next vital thing in order to be able to function and have an opportunity to have a life that is not all hardship.

1031. Health insurance is vital to maintaining your health.

1032. We have many resources in the community but people don't know about these resources.

1033. Not many people know whether or not they qualify for these things.

1034. Many people with disabilities that are still living with family members have very limited connection with community services. Also, besides the assigned case worker, no one is actively educating them about the different benefits available to them, such as IHSS hours, Medi-Cal, Medicare, etc...

1035. To assist clients in accessing their community when they get older.

1036. There are so few services in rural areas. We need so many more, how do we get there.

1037. Community based assistance/referrals are beneficial

1038. I don't know.

1039. Medi-cal and IHSS are same of the only supports middle class families can get to help their children.

1040. I like going to church

1041. I need better health care. We need more doctors

1042. I need more IHSS Hours

1043. Don't have money let we have medical and medicare

1044. More services coordinators are needed

1045. Rural areas are lacking in services

1046. Services in the community are so important and families and individuals need them in their lives

1047. Support staff crisis.

1048. Community supports, mode support to continued services.

1049. Community needs to be aware and once they are made open to help

1050. IHSS, my mother is a IHSS worker and works hard.

1051. Community supports could be Improved, IHSS, recreation, people are bullied and hurt.
1052. We are trying everything to help my grandson learn to control his behavior before his actions, we are using ABA therapy and would try anything else before he injures someone like his mother.

1053. So people know where they can reach out for supportive services

1054. If we can find a community that will help and understand that we are not alone. Sometimes we feel like we are the only ones.

1055. People need others in their life who can give them a hand and they don't always have to rely on paid supports.

1056. To get to know people

1057. IDK

1058. Church shows you want God to know that you are following him.

1059. It's important to have community events.

1060. Gatherings are important for our kids but regular community activities help our kids and more importantly raises community acceptance.

1061. Because it’s an off shoot of education.

1062. I need to apply.

1063. Quality of life, social friendships, health and well-being and healthy lifestyle active.

1064. Health Care specialists are needed in rural areas and dental care.

1065. We need disability awareness and actions against discrimination and abuse.

1066. Community integration and acceptance: we do not know where people with disabilities go when they are done with school!

1067. IHSS is a complete mess. A new type of program or help advocate for IHSS to improve.

1068. We need to be more aware of county services.

1069. Community things to do.

1070. This covers so many areas.

1071. RC's and generic resources need to be better connected specifically mental health.

1072. Formal and informal supports are limited in remote areas and small towns.

1073. Often times families have express how they lack community supports.

1074. Education to the general public.

1075. Cross training among agencies so that referral process is easier for families and they can know about us from going to their doctor.
the family needs additional supports within the community
beneficial
It has been my experience that parents can feel isolated and powerless when they have no supports to help them.
It is important for parents to understand the generic resources available to them that must be exhausted prior to assistance from IRC.
Parents need assistance accessing generic resources. A better relationship needs to be established with Regional Centers and those resources (IHSS, Medi-cal, SSI)
NA
It takes a community to improve the lives of our clients. The more the better.
important
My daily life.
Currently services for adults with challenging, behaviors are being cut back in ALL areas. Example - only 1 dentist in OC for who does sedation for adults.
Generic services like IHSS often provide terrible customer service
all people need community outside of work and family to grow socially
To help with your medical needs.
Opens up more opportunities for people with or without disabilities to understand one another.
Lack of community for disabled families
Anything to integrate our kids into the community and offer parents additional help is vital.
need all the services to support individuals
because it will help others
I like attending program.
Because I like being a part of the community.
All and any supports from the community is very important. We need to know as caregivers and advocates for our children where to go and what community supports are available. I still struggle with figuring this out for my son.
They need to feel and see the support that is around them. To thrive.
Generic and natural resources are how "typical" individuals access social, employment, recreational opportunities. Utilizing some of those same strategies would promote inclusion.

Inclusion matters.

Need more help in community settings.

A supportive, safe community is critical due to the vulnerability of this population.

The coordination of these services is intense; exposure and support understanding the programs can help tremendously.

Includes faith based services.

Medical

These types of organizations do a lot to help the community.

Their disabilities require medicine. They should be taken care of.

To connect individuals to their community.

To create and maximize agencies.

Regional centers have been a wonderful resource for assistance.

We need to help youth and their allies to link to community support that are available for everyone.

Being able to be a part of community in general is the most important thing to me. My desire for my son is to be in community.

There are no support systems for adults who have jobs but still cannot afford a place to live. I believe the community can and should have support systems in place for the "Fully Employed Poor".

I/DD is unable to be cured or received treatments without benefits.

Parents need community support, and interactions with other parents with special needs children.

These are often the supports that make the difference between being able to live independently or not or making living with parents/family manageable vs non-manageable.

Because you need to use those before you can get help from the regional centers for services supplied and medical equipment. You have to exhaust all community resources before the regional center will step in and help you. The timeline on this can run sometimes 6 months to a year. If you need a service or piece of equipment that’s a long time to wait.

Offering respite care is a good choice for care providers.
1118. Medicare and SSI is always messed up. It is so hard to get medication we need that is constantly declined due to brand name life saving drugs. SSI tried to take your SSI away and you end up going to Fair Hearing and in the meantime, have lost your housing and everything else during the 2 years. They never pay you back in the rear. Who is supposed to help us. No one. You say there are advocates but no one wants to do it. How about you have a center with people there so we can show up and get help.

1119. In our region, most SCDD and regional collaboration, event, activities happen outside our local communities. Our adults and families are less likely to attend supported events and activities, and are less likely to participate or have access to community events or activities for this targeted population.

1120. Agency linkage can be overwhelming for families.

1121. Health and home are most important

1122. Need more community support to help clients engage out in the community. Vendored Programs from Regional Centers should have a Behaviorist in place as part of their staff. Often staff does not know how to deal with clients and end up staying behind instead of going out into the community. If they were trained on how to handle behaviors in the community, clients can engage with other socially and effectively in the community.

1123. community supports could provide opportunities to learn and develop vocational skills

1124. to know the community more

1125. Always good to know what services are available.

1126. It takes a village.... you know we are all in this and the more support we can garner from the community, the more value we can add to the quality of life for this population.

**Spanish Responses (Translation)**

1127. My son has already graduated from the School District He wants to continue educating for adult life

1128. We need good quality adult programs

1129. Because many times we do not understand how to fill out these forms

1130. I need gender, IHSS and education services.

1131. Social recreation
1132. Because my son needs therapy and so far, he doesn't have it
1133. Because in order to continue growing in other areas of need, the person needed to have a stable life, housing, health care, food, etc.
1134. My daughter has medicare and I do not understand how it works
1135. It is still a problem accessing appropriate services for my children with developmental disabilities
1136. Because it is important the therapies for your life to be able to educate better
1137. Because together
1138. Our information to educate the community on how to advocate at IHSS, Medical ...
1139. Who buy according to be level based on need
1140. Changes to the IHSS plus information on the site
1141. Everything is important to the family
1142. Because it is very important that you are educated on how to advocate and Chris and Sofia are doing excellent work.
1143. Because after school age there is not much infection or support for adult life.
1144. For the health and goods of our children.
1145. Activities and supports for children with autism who recoil when they are hugging
1146. Because he is an adult
1147. Because he doesn’t know how to tell me if he is ok or what he wants at the annual IHSS appointments.
1148. This information is important
1149. Learn what IHSS is
1150. Because I need to know more about them
1151. Because these services helped him all his life. He needs them to survive.
1152. Our community is not or knows about social services or communications, when they know and are wrong for not having papers.
1153. They are more necessary
1154. Covers many topics that can help my child
1155. Because my son is 18 years old and I want training to work
1156. Support is needed for the Hispanic community.
1157. Because in adult programs their focus is not academic, they only say in
everyday life, when in daily life they also do math and they have to read
certain things that are important. Maybe in the community there are sites
or places that want to work with our adult children in the academic
because they are not ready to register for a school.

1158. For many parents we do not know that medical covers many therapies that
can help our children

1159. These services are necessary in the lives of our children for their medical
care and development.

1160. Without supports there is no quality of life, nor guarantee of having a life
like any typical person.

1161. All services are so important to prepare for the future and for the safety of
our loved ones

1162. I think it is very important to have knowledge of generic supports to help
people with a disability lead a decent life.

1163. Because these services will help our children to live better

1164. Learn what is the complete medical and C.R.

1165. Because families need a lot of information

1166. As IHSS, Medical Regional Center does not approve the services we have
these generic options

1167. Receive agency support

1168. Sometimes some do not apply

1169. Because they pay little and when my girl needs more hours I don't give it
to her

1170. The services are necessary to help our children

1171. more increase in generic services

1172. It is not less important it is just as important as housing.

1173. If offered on an as needed basis if necessary, parents will begin education
at an early age with the necessary supports.

1174. It is necessary for the support of the children and for them to receive what
they need in their community and home.

1175. How to ask for services, and the crystalline help to be able to help our
children.

1176. To further prepare parents and families of children with different disabilities

1177. Because the individual with disability needs to have a dignified treatment
Because they are the services to help and support with the needs
I found that it is easier to advocate appropriately when you have support.
How we can go about getting services in those areas
I firmly believe that it is very important example - medical so that our children are always covered emergency health
Because I want you to have Support outside the home where you feel comfortable and are not discriminated
To know all the benefits. Formal community supports
Because from there depends your mental and social health as much as the personal health that for the whole family
Because I need it I have never applied
The women who provide these services come to my girl to have a better development.
For the same reason, the supports are very important for the development of my daughter's greater quality and life.
There is very little info on these programs.
Explain well to families what these benefits serve well
Because in adult life they will need more supports
It is important to have and know the information about resources or help that people with disabilities need and that they are given with respect.
I don't know them
For the supports to our children
Because the individual with disabilities, needs treatment with dignity.
We need state supports to help our children
Because through these services, the person's life is improved.
Because all these services are necessary to help our children and all the parents.
Have more information and support in these areas.
These services are sometimes denied and you don't know what to do, where to go.
Because medical is vital for our children and for them to be healthy
Because these services are very important to help the families and the children with disabilities.
Because many times he does not know more, we call and he hears us know about our rights.

Better quality medical services and more providers that are available.

How do we have to be more informed and help is needed in this matter.

Because with supports children support and improve the quality of life.

It is important to have access to the formal services that can be obtained, because there are always long and difficult processes that many times people cannot access the services.

More information is needed more help

Because those programs are the ones we are going to spend the longest.

Because they are the services that will help the most in the future of our

That the individual with a disability has access to services accessible upon admission if he arrives.

Because they help us with the liquid.

So that they never lack medical support and are always properly cared for.

It is very necessary for our children and for everyone.

Let them allude to their needs.

I like more medical and for medical services

It is very important for me for him to have medical

Because I need support browsing systems

Because all these services are very accessible

Supports to live well with disabilities allow my daughter to take advantage of an education knowing that her other needs are so agreed

It is very difficult for a regional client with functional autism to obtain services such as SSI, DIS Bus passes, etc.

Why does the child with disabilities need support from programs like this as well as parents to help them more?

Because it is an important support to take care of my daughter's health

For IHSS to count as co-pay

Specials must be well prepared to get ahead

How to Qualify and the filling of services

Because they need more support in the community to get out and become integrated.
Health and aid is basic

The financial aid of the SSI is very necessary for the community to pay a house rent for example. IHSS is very important for moms.

As IHSS, because we need these Services for life, for health

Services are very important

Because we need to learn more

Helps the family's quality of life

Why is there ignorance

Health is important and the hygiene is also very important

Services for two parents to improve the child's living conditions and have additional support for the father

It is important to know and know about the support and services that support exists so that special people have a better quality of life

Training and support for the needy individual and families

Because in some places they do not see or serve schools to be 'ecuielodonor’ (illegible).

Because it is important that parents are informed in the Services their daughters can get in California

The more information and in these services they can have a help that many times we do not know or understand.

Will be needed for your medical care.

How to qualify and service filling

My children do not qualify for medical and although we are low-income according to their system, they are not eligible, and they are children born in this country.

Why do we sometimes take help in how to navigate these services

Many families do not know how to access generic services.

Because it is very deficient they look for services in the community that are accepted with inclusion and accepted

I believe that making them adapt to the community and the community is educated and supported.

Charitable services do not cover services such as ABA therapy, for dietary services.

Our community has to integrate our children with special needs.
1251. Because my son is very implicit in life
1252. For there is a lot of misinformation in the community and very little sympathy for people with disabilities.
1253. To involve our children and participate more
1254. Because they are very important camo MediCal support
1255. Because we need more supports than that and there is no way to get the supports.
1256. Because medical is important

Park of the diagnoses if acknowledgments
1257. Because you need more therapies to help children with needs. And more programs outside of the house in parks and community.
1258. Be aware of benefits (regional center must prepare information for parents and children)
1259. Because it seems that with Apollo the children go out and learn more
1260. Because services are very important
1261. Self-esteem support, independence
1262. Support is important
1263. IHSS support for parents’ medical health and coverage for therapies
1264. Because while they receive support from the community and they are passive signal for them.
1265. Sometimes families do not know that there is help for families and the programs that exist.
1266. Because adults and adolescents need a lot of support in the community
1267. Many of you see the information that we do not understand. We need to know more details about these services.
1268. Because the family is important for the development of children
1269. There are not many in this area
1270. Because the community’s resources are very important

Japanese Responses (Translation)

1271. The attitude and attitude of the accepting party for community and social participation are important. Even if parents try hard to accept children,
they cannot do it alone. Community and social acceptance are indispensable for people with disabilities to live a more fulfilling life.

1272. We need more support in all areas. Without sufficient English language capabilities and cultural differences, it impacts all kid’s chances to receive

1273. Jurisdiction over school district is over I want more information

1274. There are times when the mechanism of Medi-Care / Medi-Cal is not well understood.

1275. Because it is very important to live with society and get to know others and the children.

1276. IHSS and medical are very helpful.
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FORMAL & INFORMAL COMMUNITY SUPPORTS

Question 2: What types of activities would you like SCDD to focus on?

1. Educational Advocacy, IHSS, DOR
2. Supply funding for the programs.
3. More hours for IHSS.
4. Need to do this well to maintain basic access
5. make sure the program continues
6. More training for specific rare disease cases. parents need help in this area. For example, we have sown syndrome, CP, resources out there by case for rare disease Not so much in EAST LA area.
7. Community support generic services and bow to access them.
8. online resources for families
9. Information sessions for the community
10. Training on the new changes from DDS to providers, webinars and in person
11. More help, low income, better sidewalks.
12. Social activities as well as music or cooking activities
13. I will that SCDD will help individual personal take the help to them at their homes to hear for the needs
14. Access to social activities and recreation ADAA compliance
15. I would like to get a booklet of information put together. which could than be given out showing information a special need person and the family or caregiver could use.
16. Help maintain medi-cal and medicare for our clients
17. workshops, trainings w/ variety of cultural adjustments & language
18. Outreach to the city to ensure as the city/county grows they have the support to the increase of residents
19. more services are covered under medical
20. Job fairs, hands on job training
21. Trainings
22. How to get volunteer opportunities
23. ensuring individuals can do what makes them happy w/o so many restrictions
24. How to keep medicare
25. information regarding these different programs
26. if I could communicate better w/ people I would help people to go to work. Help them pay attention better & turn off cell phones at work.
27. Try to get electronics so I can do research on things I care about
28. Knowing what medi-cal covers, accessing the call center at Medi-Cal because the wait can be up to 2 hours & sometime person who answers the phone doesn't help.
29. Make sure the child has sufficient income to pay for food, rents, ...etc. & be able to visit a medical facility without paying too much money
30. Individualized 1:1 services
31. Let parents know IHSS is based on eligibility of their child's already established disability under state definition - IHSS LA County minimizes and does not help them establish eligibility as they should - tell parent they are saving the state $; they are not begging to be paid - their child my qualify on their own needs. IHSS social workers do no comprehensively assess.
32. How to access
33. Classes that teach me things I don't know how to do.
34. learn how to stay health help find volunteer jobs
35. Events/advocacy
36. Dance
37. Training on how to navigate Recreation Centers
38. Where to find support in my community.
39. Quality providers with training and pay that helps to mitigate burn out.
40. Continued and more information and clearer information on self determination and timely roll out.
41. More volunteer options.
42. Cleaning table and chairs.
43. Increased funding for services.
44. Train self-advocates.
45. Advocacy for collaborating better and reduce fraud, scandals, and loopholes in insurance.
46. More ways to improve the life of clients, more resources and support can improve self determination.
47. Mental health
48. Senior disabilities.
49. Medical and medicare because being sick is very expensive.
50. More outings
51. More information readily available.
52. Training in signing up for assistance.
53. Provide more information on this
54. Sadly, the basics (sadly because so many families are still unaware) like IHSS, medi-cal, Medicare, and SSI/SSA.
55. Community fairs/outreach opportunities
56. community supports, local orgs.
57. IHSS have us keep are
58. To focus on the services that prioritizes on their everyday living that can benefit both those people with developmental disabilities, as well as their families.
59. Regional Center & benefits
60. Quality of life towards well-being
61. more indoor and outdoor activities for the clients
62. Art classes/Home Ec.
63. seminars, educate clients & their families
64. workshops and education
65. Help make the application/renewal process easier & more transparent
66. The share of cost for Medi-Cal is ridiculous and the threshold for what is considered in excess of "Maintenance need" level of $600/month has not been adjusted since 1996 and the State of CA has not applied a cost of living adjustment since 1989 (better known as the "Share of Cost Cliff that affects seniors and people with disabilities). Because I'm divorced and receive child support for my son, I have to pay a huge monthly share of cost ($731/mo), while wealthy married couples do not have Share of Cost, no matter how much they make, because of their marital status. I'm penalized for being divorced. And there is no other medi-cal category that my son qualifies for. I have spoken with many at Placer County Health and Human Services that think this is a flaw in the system and just plain wrong. I'm not even sure that those who created the various Medi-Cal Eligibility categories are aware of how this flaw affects single parents, simply because Child Support is considered income to the disabled child and the threshold has been sitting at $600/month for years.
67. Promoting awareness, assisting with access.
68. Saturday Night Live and Jeopardy
69. Protect and strengthen these programs
70. Medicaid, IHSS, other similar services.
71. hands on
72. Better pay for support
73. awareness/events so people know.
74. Training classes
75. Not sure
76. Guest speaker at Progressive Resource
77. Training
78. Continue to promote and increase the funds.
79. Just stressing the importance of giving back
80. Safety planning
81. We need better pay & benefits for IHSS workers, because these workers are crucial for us to live our lives independently. We need more $ to live on until we can get gainful employment
82. raising wages for working ID/DD, services - more variety in program options - case managers having lower caseloads
83. It would be nice if they consider more place or open up more centers for this population.
84. Mind games such as puzzles, board games
85. More opportunity to learn via class, conference, etc.
86. family based & community setting supports
87. Trainings, forums, conferences, surveys, newsletters, interactive webinars
88. An in-depth interactive workshop.
89. You already take care of them
90. Provide access to information about early intervention, workshops and info on social media platforms
91. Social events/day program academic focus
92. Funding & granting of more programs access service areas. More hours for clients who require it.
93. providing health assistance plus assistance to parents
94. Spreading as much info as possible.
95. I am interested in your plain language information
96. Continue to provide IHSS and Health Care including dental
97. Going to the library or gym
98. Proper funding
99. More funds for day programs and jobs
100. Trips, our consumers do not get to see outside their world.
101. Direct support personnel, their training and wage is critical to my daughter’s wellbeing, quality of life and ability to be safe, happy and part of community
102. social skills and job skills and living and being on your own.
103. Benefits for dap to increase employee pool for people with dd
104. Getting more pay for medical help.
105. Autism friendly activities and programs for teens and adults
106. I don't know
107. More meeting for the developmentally disabled(recreational).
108. Make sure they are working
109. More information and assistance applying
110. Health insurance, SSI, Regional Center education
111. advocate for continued benefits
112. Increased support in this area.
113. Create an up to date resource guide of all available services for people with I/DD on our region
114. Workshops for parents on obtaining community Services.
115. Continue with self determination type funding so families can decide what best meets the goals of their loved one.
116. Educating and connecting service users with community supports.
117. Teens and young adult activities.
118. Community outings
119. special Olympics
120. Help to get services. Not just workshops
121. Finding resources and getting the word out.
122. Job training and social recreation.
123. Higher rates for service providers, higher wages for direct care workers.
124. Education on supports that may be available.
125. Resource and referral. Providing information and access.
126. Liaisons for community volunteer programs so consumers could find one that fits their niche; advocacy for greater MediCal participation by providers
127. HCBS, IHSS pay in LA, educational materials for generic resources such as park and rec and churches
128. IHSS
129. Better IHSS, providers are hard to find because of low pay, no benefits, some have to wait months for paychecks. It's not fair to them and their work is not valued by the State.
130. All available services separated by 30 mile radius.
131. Help families access programs for people with disabilities, to have more foundation, in schools for children with disabilities and support in the IEP
132. In workshops, list of educational clinical resources.
133. Having it more easy to access
134. Training and providing additional supports
135. trainings
136. comprehensive IHSS assessment- parents accept, what an IHSS worker calculates, without it being comprehensive and accurate- a family’s life can improve dramatically with this service- L.A. county IHSS office is many times is a disservice to regional center consumers; minimizing consumer needs for assistance in their daily lives, not helping establish eligibility, but neglecting to take vital specialist information into account.
137. Any really
138. Identify and support local programs/community organizations to reach out to serve individuals in the community
139. Family support: information about services for their child, advocacy, respite, advice for SSI/Medicare/insurance etc. Very complex situation for families that will change when their children become adults, and/or the parents get old.
140. Less fragmentation among agencies tasked to help our kids
141. Too busy to get help.
142. government subsidy, public private partnership, taxation legislation
143. outreach activities
144. Social workers to help fill out forms
145. informing families of supports and how to qualify for them
146. all
147. More choices for Adult Day Programs and longer hours.
148. Provide the watchdog services the area boards have done in the past
149. Housing and hire wages for service staff.
150. Longer day programs, higher pay for workers
151. Making a valued, properly compensated career path for support staff, SLS, ILS, Licensed care providers, etc. We need all options and we need them to be high quality.
152. Can't find staff due to low wages. Too much staff turnover - they need to be paid more! It's an important job but not reflected in wages. Move to get higher wages for service providers
153. Provide better insurance and dental and prescription plans
154. Practical skill training and outings
155. Plain language workshops, areas to apply and advocate.
156. IHSS, Medical, Regional Centers, Social Security
157. Local community liaisons acing to educate and promote for services to community members.
158. Help with the process of getting SSI
159. Job coaching
160. Volunteer, flexible employment
161. Job transition and training
162. JUST GET THE coordinators to do their job and not lie
163. Ease if access to these supports
164. Medical, IHSS
165. Help create navigators to make it easier to access these services as needed
166. Quality and expertise
167. Agencies that can assist with either micro-businesses; independent living skills; or agencies which provide assistance with independent living and/or group homes.
168. Firstly, help in rural counties developing activities of interest for the physically and developmentally disabled and seeing that caregivers can get reasonable pay.
Ensuring Regional Center continues its services
Most of these issues are all very important
Connecting people to services
It's important.
Focus on how to get care to rural areas
We need to know if a doctor knows there is the possibility of a parent having a disabled child at an early age - information would help all involved
Raising the pay rate. Service providers don't get paid enough. Increase the Pay raise for service providers.
Restructuring DOR so people can actually have access to it. Have a Livable rate for care providers in independent living skills, job coaches, respite providers, behavior list, therapist, to have some kind of consistency rather than a high turnover rate.
raise pay for IHSS
Education for parents and service users.
We need more help for people who get SSI.
Yes, keep me here. (OPARC)
People should be able to go out and do what they want to.
Give more money.
I don't know
More financial support.
More money for supports.
Making sure that DD programs are identified and reached out to.
simple trainings
Medi-Cal has limitations on what is covered. This needs to be expanded. There is a huge challenge in finding evidence-based programs especially in some of our rural areas.
Community-based, individualized based on person centered planning, available to folks regardless of skill level, behavior challenges, etc. supports that help people grow and develop and find their place in the world.
I need to check on the ARFs to see what's going on with our money.
IHSS
Supporting appropriate support. from primary care doctors, supporting community and volunteers.
Addiction and mental health services for follow up resources post partum.

social reservation

Education.

Drop in sessions for clients to be a one stop place to fill in forms with an availability copy machine and a list in advance to explain what documents to bring with you

Workshops, Education, Outreach

Doing a great job!

offer more resources

Helping families advocate for the Benefits that they will need to maintain their children in the family home.

Availability of services

create new resources

Transportation for example. Most consumers do not even know they can get Lyft rides to and from doctor's appointments with Medi-Cal and will call their Regional Center workers asking for a ride.

keep doing outreach events

Advocacy programs

I don't know

I'd like to see that these supports will remain in existence for as long as it's needed

identifying organizations or franchises willing to work with our moderate/severe population.

I don't know

go shopping

More social activities for people with intellectual disabilities like autism.

To inform the parents that these services are available and educate them on how to get the services so their child can get the services as soon as possible. I would also like them to follow up and make sure the client has the service within a reasonable time.

Caregivers not on their phones and interacting with persons served as they, ride bus or van, malls, parks beaches, restaurants. Getting training in appropriate behavior and interaction with persons not in care giving position

gay activities
215. How to start community action groups relative to targeted needs (parents
groups, self advocates groups), and decide to target.

216. Training for parent for IHSS services.

217. Increase pay for IHSS workers- with the increase in minimum wage, very
difficult to retain workers thus the program isn't actually serving the
disabled.

218. Community service opportunities

219. Need more parental support who have children with disabilities.

220. Health care for IHSS providers.

221. please tell me what type of supports available in Palm Desert like, drivers
and care provider to accompany our daughter

222. new laws, new procedures, education

223. helping facilitate getting these services instead of sabotaging

224. Attorneys and litigators continued work for federal and state programs
toward supporting those with disabilities.

225. Summer Camp

226. Community integration and "buy-in"

227. Possible finding for our families and clients a different way to provide IHSS
services that is less adversarial. The Counties in Calif. quietly blame the IDD
community for "piling on top of a service that was meant for only seniors
and adults with physical disabilities". And when someone defrauds this
system; we are looked down upon as being "just like all the rest". And
recently IHSS has been taking away hours for the services we receive
through the Regional Center to the point that even though the law says
otherwise, the State Hearing judges are ruling that Regional Center service
can be counted and IHSS hours can be taken away. Which increases the un-
paid hours that caregivers have to provide. Which in essence creates a form
of State run human employment trafficking. Complete with threats of
punishment of being jailed if you make a mistake and don't do everything
right. We are supposed to be the greatest Nation in the world and this is the
best we can do??

228. Raise awareness of consumer needs with the respective departments so that
systems and programs can more readily accommodate their specific needs.

229. Outreach in all counties, be accessible.

230. IEP training and IEP support at the meeting

231. health and wellbeing
232. respite, IHSS, medical, therapy support
233. MORE HOURS
234. life skills/employment
235. build relationships and connections
236. More hours for IHSS
237. help MediCal and MediCare address errors in consumer eligibility which leads to discontinuance of health care
238. community support resources
239. training, get togethers to socialize, networking
240. More benefits for our clients including undocumented clients
241. To do fairs or an organization to bring information on IHSS, Medicare, Medical, for the community in both languages
242. Informing on the rights of the individual in regard to health insurance
243. higher wages for ILS and SLS, more community based projects
244. promote more inclusion in the community, keep policy makers informed about disability issues
245. funding for outings
246. places friendly to integrate those with DD
247. trainings or conferences focusing on health and prevention from different diseases
248. More adaptive activities with individuals with a variety of disabilities
249. A resource - Education & outreach not only to families, clients, but to service providers too
250. More workshops of different topics of autism
251. Focus on making sure that they provide all the medicine and tools that the patient needs
252. help us not lose our insurance eligibility
253. help in accessing insurance services
254. Focus on making sure that they provide the medicine and tools that the patients need
255. Don't know
256. Some info comes from professionals, but often it's word of mouth between families. So, profs. need to shar more (and not ALL the info. in one mtg - it's too much, we can remember)
257. Go to church and have dinner there
258. increasing more support groups or awareness groups
259. Increase availability & include people not getting services now
260. Expanded one-on-one supports/activities for those who are inappropriate or ineligible for day programs due to their disability or mental health.
261. Training/workshops for persons served
262. More opportunities & encouragement to participate in major religion & other organizations
263. Provide more information
264. Information booths
265. Work (volunteer) on farm, growing fruits/vegetables, caring for animals, selling products at farmers market. Or other alternative meaningful activities.
266. caregivers will cont. to be able to give medical services in-home
267. More social connections.
268. free activities in local areas that will provide fun or useful info. Help community organizations and churches start programs for individuals with disabilities
269. workshops/pamphlets
270. assist individuals in identifying resources available to them in their neighborhood
271. Information & help to navigate HMO's
272. anything is mostly needed.
273. social, recreational, skills/job training, technology training
274. Provide a list of "safe supports" w/in community
275. Help clients stay informed. What services are available for them. Activities to help them know their rights, how to ask for what they need and who to go to if they need help, on being mistreated.
276. Train people how to communicate with special needs children.
277. Lobby the government to increase salaries for these workers.
278. More information on how to receive services for people w/ disabilities
279. More SLS ILS support. Also health and safety out in the community. How to handle yourself out in the streets.
280. Lunch/dinner meetings/groups. Volunteers, feed the homeless/food pantry. Festivals, amusement.

281. Bowling.

282. Informational booths in communities

283. Ensuring healthcare

284. going to community more
- more people who know ASL

285. Creating better/easier to navigate our infrastructure available for all/not only those who have loud voices.

286. Funding of support.

287. More social events

288. training in person.

289. Provide education to help us understand what is available to us.

290. Apply for benefits

291. Facilities who offer workshops, internet access and case managers.

292. Support that is easily accessible for the client and families

293. Medi-cal - glasses for clients over 21. Dental services that are to repair teeth rather than extractions. More opportunities for the community to volunteer with people with developmental disabilities.

294. Create a website of resources

295. outreach, training, accessibility

296. Strengthening Medi-Cal/Medicare.

297. Have workshop where families fill out their paperwork with guidance.

298. To provide the consumer.

299. Reinforcement for the medical benefits of the disabled.

300. More transportation to appointments

301. Bringing more support

302. How to sign-up for these services like health fair.

303. More information, flyers, and awareness.

304. Sports

305. More information on things

306. Anyone can go volunteer at a dog shelter for example the Humane Society, or also volunteering at the park cleaning and playing at the local park.
307. learn about cheap insurance
308. to be more flexible to when it becomes to medical and when you go over for 3 dollars and you have to pay for the medical and co payments
309. Educating the community on the services these agencies provide.
310. Community advocacy, engage employers in the community to participate in employment efforts of the regional center.
311. Extracurricular activities such as arts and dance.
312. Continue the advocacy to maintain, enhance and add to the current support structures. This would also include increasing wages to care providers to attract and retain quality caregivers.
313. Faith based services have more programs and inclusiveness for people with disabilities.
314. General education of how to "navigate the system" and what services are available for families.
315. may be a once a month community outreach program that would have informative classes. Like riding the local bus, how to shop, basic maintenance of disability equipment
316. Follow the early head start model of inclusion
317. I don't know
318. Housing
319. vacations
320. see above. We live in splendid isolation in rural, area and there is no day program, no respite.
321. to know how to do it
322. Make sure it stays.
323. More funding
324. Options that expose my daughter to others within her age range
325. Help families understand what self-advocacy truly means. That it doesn't require families to STOP helping their loved ones but it means helping to empower their family member with I/DD.
326. Medicare
327. want to be assured to have low copays and to help find a closer place to volunteer
328. how to apply for government assistance, more classes on that
329. Helping individuals become more knowledgeable about the services that are available to them & making them affordable.
330. Volunteer activities, community groups (for social skills as well as friendships)
331. Bring aware to those who don't know they have these options
332. Accessible services
333. more awareness of the services available
334. Providing information on community support
335. More Legislations.
336. Health Fair's advertising support in area.
337. Fundraising, medical awareness, how these services benefit the people
338. have more people work in these support services
339. Don't know.
340. I AM NOT SURE
341. Better training for the employees. I've seen and worked with great people and I have worked and observed others that lack the basic skills and training!
342. more community outreach and a list of services
343. Create new & better housing for severely disabled people. We need more options
344. Parent support through education on how IEP works and where to go to get the process started
345. MediCal Insurance, medical support
346. I learned job skills; interview skills my staff worked a lot with me to get my job and also she works with me to keep my job.
347. We need more staff.
348. helping how to make appts.
349. More help self control
350. Again, meeting one-on-one with employees; getting to know and recognize their most important needs
351. a reason not given
352. Fund parents' supports choices more freeing
353. Educate the community with the importance of accessing available resources in the community
354. Make sure information is available
355. Pathways from diagnosis thru service types. Pitfalls w/in service types/coordination
356. Work with SSI to help fill out documentation and coordinate ease of applications.
357. educating families about services, advocating with funders for more funding for services
358. find out why and fix it
359. Advocacy and healthcare assistance
360. More help getting this info out to the communities
361. Having an easier time getting any medical assistance for the clients.
362. Access
363. More positive support systems.
364. Getting the person connected to some group of people that accept them as part of that group.
365. Figure out ways to help instead of asking me why I moved to this town and telling me to figure it out myself
366. advocate for core staffing reform
367. Anything can become a learning activity .... eating out and making their own order, making a purchase at a local store or market. The problem I have seen over 30 years, staff uses community outings for personal time, staff on cell phones while the group is just sitting without books or direction, clients sitting on the floor of dressing room floor while staff was trying on clothes. My hope would be that staff needs to identify objectives for ALL clients and goals for the activity. Seems to be little accountability with community staff.
368. more health services
369. reform on regional center funding, it has not been addressed in a long time
370. reform to the cor staffing formula so that more service coordinators can be hired.
371. make sure the services continue
372. community resources
373. Job, behavior and social skills practice and support to ensure maximum independence.
374. Increasing formal support options
375. HELP AROUND THE HOUSE
376. Formal support for health and welfare, informal support for jobs, housing, activities, etc.

377. assess how diversified the support networks are of people with DD and look for areas to increase diversified opportunities

378. how to fill out forms

379. job skills

380. jobs

381. jobs

382. Focus groups, presentations, formal meetups with key leaders

383. Addressing the barriers to these supports and breaking down walls to access them

384. Education and Advocacy

385. More popular things

386. more resources and awareness of resources for families

387. promote wellness

388. Group activities that allow people to feel like they have someone to talk to.

389. Not sure

390. Marketing and promoting awareness

391. The rate study must be implemented now

392. To have a handing off approach for the participants. Every one working together.

393. Regional Center activities, faith based programs and activities, after school activities, Parks and Recreation programs, Senior Citizens Programs

394. Support groups, one day retreats/meet up for caregivers

395. going places

396. more services

397. funding for cities to offer dances with a DJ 4 times a year; take a group to the movies and lunch before or after; bowling leagues, excursions to Ball Games or plays. Basketball groups, fitness classes

398. resource sharing

399. Provide more apps assistance.

400. More community supports

401. more culturally and linguistically competent supports that are easily accessible
I'd like the process of applying and maintaining benefits to be easier, it is paperwork nightmare.

Ensuring that it remains available.

Education courses for the general public

Take us shopping and farther locations.

Funds for service providers to provide these services and continue to provide them.

Group therapy and individual therapy services for both urban and rural communities

use social media

Ensure Lanterman Act funding

opportunities

Art appreciation, drama, music or even an academic class that would allow modifications for students with special needs.

Counseling

Educational and social recreational activities

providing lists of resources for families

Make sure there are services for people

increase the funding for service coordinators in regional centers

revisit the funding of service coordinators for regional centers

What does the Medical cover as if it were on medication?

What course do you give?

IHSS

advocate for core staffing reform

Workshop on general information on existing supports in the area

supporting agencies like Special Olympics

respite, dances, exercise

Health

Not sure

create a list of resources for everybody

Mental health, transportation, education, and more flexibility in getting service funded through regional centers
429. Mental health, housing, transportation, education, flexibility in service funding through regional center's for rural areas.

430. more hours and pay to find better and qualified providers

431. Make the Structure of pay something that is equal to other professionals and provide good training. Act like we really DO value these people and not like we are checking a box on a list.

432. see below.

433. Advocacy to benefits that people can use while people work and connection to volunteer activities.

434. Increasing funds to educate law enforcement. Holding law enforcement accountable.

435. Awareness campaigns.

436. We need more funding to assess the impact on adults with autism and other developmental disabilities who are aging and will be without family support or connections in the coming decades. We need to consult with social science experts, policy experts and state and local governments to fund solutions to ensure these members of society have the opportunity to be full members of society.

437. more conferences,

438. spreading generic services

439. Developing community forums and advocating

440. Help with navigating gov programs and awareness about what programs and funding are available

441. A full understanding of what support groups and opportunities are available. From lists of camps to faith based to support groups. Even this questionnaire--it's by chance that I found it

442. Grants to existing nonprofits

443. SCDD needs to STOP favoring the high functioning, verbal self-advocates and focus on the desperate families who cannot care for their severely challenged adults.

444. going to movies

445. to go to Doctor and Dentist

446. Communication with community services (ie. libraries, recreational departments).

447. Not sure if any

448. Info sessions designed to help people get services
449. Show why this child needs help
450. I have not dealt with IHSS in Bakersfield myself, but I have read the terrible reviews online and heard other families’ experiences on how bad the office is run.
451. I would like him to have New Horizons even if he is living with support but not in family home. He thoroughly enjoys this resource. It’s been a huge blessing.

452. Supports and trainings
453. Better funding from state
454. Events held where people with special needs can volunteer/help
455. whenever possible reminding SAs and FAs that they are addressing the "whole person" needs when identifying needed services

456. See that the State Council focuses on: Formal and Informal Community Supports, within the Next Five Years.
457. Streaming and mingling w/ normal people in a normal settings like community events.
458. An easier way to get organizations to the individuals that match the disabilities.
459. More workshops on the different agencies and community resources.
460. Expanded opportunities to learn to function in the community, for example, supported public transportation, shopping,
461. Training and conference expo. Community events to promote awareness.
462. Help fix IHSS or Stop making providers have to deal with this. We are risk of being sued for staff not receiving minimum wages
463. Park activities, field trips.
464. Assisted social and recreational opportunities for our loved ones in a continuous basis
465. Some Regional Centers offer group social/ speech therapy language programs. Others like ELARC do not. It would be beneficial for regional centers as a whole to adopt such a program
466. supporting coached employment
467. Focus on developing a streamlined process for the DD population to access and for those who are supporting the individuals.
468. whatever you can think of
regions, cities, counties should have multi disciplinary meetings to share resources understand services and put faces and services together. As a regional center service coordinator in a rural area to many times we are unaware of other entities from APS, School resources, Sheriff and Police resources, along with behavior health and healthcare resources.

more support and services

All formal supports need a mechanism to prevent loss of services where the client does not / is not capable enough to respond to phone calls or letters to set up annual reassessment appointments.

Assist individuals with utilization of health insurance and navigating health care provider organizations.

more health and resource fairs.

Let CA residents know about it.

Have a random QA visit to people with disabilities still living with family members to make sure they understand the benefits available to them.

Improving quality community services.

help in addressing the issues

volunteer work

yea - help with insurance and getting Medi-Cal.

Bridging the gap in available services so families do not "incense out" when both parents work.

help with rides

Find providers - they need more money

We need attention to less populated areas.

Professional status of DSP

children

Community programs get WTO to public with media.

Help us to find a way to communicate to my grandson before he injures someone! He hears and can repeat our words, but it does not change his behaviors. Drugs help a little, but heaven help us all when the insurance will not cover those meds! It took 6 weeks to get generic Abilify covered. If the prior auth needs to say something specific, then why don’t they have someone who could help to ask the right questions? Who pays for the injuries (bites and broken bones and broken furniture) caused while waiting for insurance to cover medications.

Information packets and information meetings
489. Letter or fliers send out to homes.
490. Develop volunteer programs where people can have develop relationships with others.
491. Do presentations
492. Assist with medication co-pays
493. Help to keep the church clean.
494. Resources
495. Get stores, grocery, Targets, Walmarts, etc. involved
496. Information sessions and resources.
497. More events, activities available in music, arts, and sports.
498. Do not know
499. Coordination with local activities providers to arrange for inclusion events.
500. Taken to their places.
501. more services the merrier
502. focus on bringing the agencies together for wraparound services. work on relationship with mental health as it is adversarial in many areas of CA
503. More community supports group.
504. conferences and cross training.
505. Either online or in person, have a program that would illuminate the role of the school, the regional center, medical and mental health, and how essential communication and follow-up are in preventing poor outcomes for the consumer.
506. Funding for training on generic supports and how to apply for each one.
507. Mutual Trainings so all agencies can understand each other and how to work as a team to service our families.
508. Community events offered on a more consistent basis. But the events have to be fun and engaging to foster the community engagement that we are working towards.
509. Work with regional center and other agencies to see what can be done. All areas - housing, day programs, employment, health, affect.
510. Accountability over IHSS
511. group activities, social interaction activities
512. Self care for family members & respite options for those that don’t have many RCOC respite hours
Autism/All-Abilities Awareness/Togetherness programs

advocate for funding of services

transportation

More money for programs

To go out more in the community to shopping centers like Costco.

For me I would like to know about athletics for disabled children my son has epilepsy and was recently diagnosed with Autism, so would love to know programs that would work for him. Also, social events with boys and girls my son goes to a private non-public school where there are only boys in his class. He is now 15 and would live social events for boys and girls with disabilities. These children still want interaction with the opposite sex to be blunt and really need social events like this.

Sports and social activities that include typically developing people and special needs people.

Include some/more upcoming community events and programs in your e-mail blasts.

Opportunities to create inclusion in existing community settings.

Safety.

Inclusive community events

Coordination - advocates, software, case management, etc.

Make sure they have activities to do/attend.

outreach/connection opportunities

Continue to fund and support regional center.

Anything that will support inclusion with typically developing and other developing people in and out of school is wonderful. To have access to various programs that support fine motor, gross motor and speech skills. As well as life and social skills

More affordable housing.

Make eligibility available with less requirements especially for I/DD

Classes for parents while fun activities for children with disabilities

Training re community supports not just at SCDD events but at other access points in the community: schools or other organizations where families already tend to be. Also imperative to do this in places or organizations that are centers for immigrant families who may be scared about accessing benefits and need education what they can safely access and how to do it.
533. To make it easier for community resources and SCDD to coordinate when a service is not a community resource.

534. IHSS, Medi-Cal,

535. Set up drop in centers all over the counties so people can get help every month.

536. Look at a yearly calendar and provide duplicate events or activities throughout the counties within the region.

537. Weekend programs.

538. volunteer and job coaching, mentorships, and educational programs for young adults with autism

539. advocacy

540. to know and give us information on what businesses or organizations are willing and able to help

541. Create a "Get Involved" marketing platform, "know your community" and/or "how we make a difference" session.

542. focus on programs that are still in existence and see what they need to stay afloat

543. More trainings, people don't know what they don't know

544. Training that can help people build bridges to community partners, Roundtables for Families/individuals to share learnings and expertise

545. Have information fairs were people can learn about health services & the types that can benefit them.

546. Workshops.

547. more services dental hygiene, psychiatry, etc...

548. medical funding included

549. I think here again, helping people to "connect the dots" across agencies might be something state-level could help with

550. meetups, etc.

551. Examples, testimonials to earn Regional Center Services for example. From the IHSS for example protective supervision

552. resources maybe

553. outing to refresh his environment

554. Stop budget cuts to this area. Understand that it takes longer than what they estimate to do housework

555. Community inclusion
support self advocates
Regional Center support
list all packages with referral
more authorized therapy services for kids
My people seeing my art & learning my story
Affordable housing opportunities
More facilities to access support for clients
Community partnership
Not sure
I would like them to focus on how to keep and maintain yourself in a capable position
Start more programs like the arc, funding for staffing
more opportunities to share my skills in community
Tailored Day Services
Spreading the word and training.
To make sure I am in charge`
Involving local businesses and organizations to share the services they offer in an open house forum
Volunteering is huge. IP employment is not an option. Immediate consumers should understand the importance of volunteering experience on their path to employment
ABLE accounts/ SSI
Protecting the above services
Resources, jobs, advocacy.
Workshops
Parties and social gatherings.
Presentation/information to access info on this easily.
Training on health care, IHSS, faith-based training.
Go to palm springs.
having social groups that are safe space for clients
More educational fairs in our community.
Better services and education of special needs people.
Medical
585. More outreach re: benefit services develop more volunteer activities for clients Companies don't/shy away due to insurance issues

586. Training for staff working in this area and aiming to reach as much people as possible.

587. MOW

588. Affordable healthcare and service.

589. Medi-Cal should be accessible.

590. Educate self-advocates.

591. More ways to meet new people.

592. Continue classes and programs for health and wellness.

593. Information on how to access aid services.

594. Educational trips

595. Health care

596. More referrals

597. Have more resources, for healthcare

598. Workshops on how to obtain services, eligibility, paperwork, who can help etc.

599. Caregiver respite, adult day programs.

600. Exercising, arts and crafts.

601. Giving back to the less fortunate.

602. More activities/fellowship with information that will help with needs.

603. Health care for all.

604. Not certain what resources are available.

605. Provide more activities for people with I/DD.

606. Employment

607. Finances and paying taxes

608. Reading learning programs

609. Try to balance formal

610. Transportation to facilities.

611. More community integration

612. money management, games, outing, for the intellectual disability, and transporting

613. to get more information
Finding ways to facilitate ways for communities to understand more about disabilities and how to be more inclusive by ensuring community activities allow for disabilities.

Any financial support which will help so client can pick and pay for what he wants to do. There isn’t appropriate service from agencies who can’t give services. My son gets nothing. IHSS is good as it is but my son gets nothing else - not from IRC but they actually cost us money. Give us the money to spend for my son. He needs therapy PT, boat trips, communication device and speech therapy, special equipment medication and specialized activities he is not getting that IRC keeps denying. He needs a computer for communication - we have nothing!

Transparency in assessments. Realistic individualized options for IHSS - SSI - Programs/supports available through SDRC

Volunteer and social activities

Help sessions - Call support

options focused on health care

Because there needs to be help

More services that are holistic in nature - would be helpful if these were recognized & covered by Medical/Medicare

suggestion would be to have once a month workshops to assist w/ application to guide them with the specific guidelines.

Helping disability people in need. who are in trouble with funds and more resources. Also help community colleges with funds so we could have more and better education.

Focus on outreach to general public to heighten the awareness of average citizens to the presence of adults with developmental disabilities.

A phone number with people that can provide the help. Help the ball not get dropped.

Have an affinity roommate search app by county, city, neighborhood.

Train mixed teams to lobby state, county & federal officials on what needs to be done!

Access to sports and city colleges. Not physical but financial.

advocate to legislators to protect this necessary benefit

Address the core staffing formula.

More trips

IPP trainings and how to prepare for fair hearing
I don't know

Hoping to eventually not rely on it

This is fine, just keep it up

Medi-cal/medicare for those most in need

Maybe a liaison or volunteer, trained by SCDD or something. I know the Alta workers are over burdened, but maybe we need more. Or some other workers to help them. I'm not sure.

- Talk to agencies to get their ideas on how to improve & what people w/ disabilities can do to access services

More awareness about support for families like mine who support me

weed

Medicare

Nurses’ visits at their homes - Representatives helping low income parents with low education filling out applications on schools, using different languages

Incentives for more people to get involved

Support the IHSS union and demand higher wages

internships with more wide range fields

Help to understand official paperwork and legal papers.

more choices for insurance

Community Services

More drives to educate people on these services

a reason not given

IHSS, respite, advocacy for self determination

More facility - Training - Housing

Trainings so that individuals know their rights/how to advocate for services

Resources and Funding

Outreach, compliance, communication with regional centers & families. Have a mentor for each family.

Information fairs, and information sheets

More support groups for families and patients

Doing something to support the community.
Outreach efforts from the schools and the communities. Allow companies to start sponsoring classrooms.

Continue IHSS and Medical is very important support for their survival.

IHSS, ILS, SLS

Get creative and help agencies recruit and educate and pay support staff.

Early access

Continue current programs

Store, doctor, prescriptions

To learn new things

Legislative advocacy, funding innovation consumer/leadership.

Activities to show us how to go about getting i

implement the rate study now, and work to have trailer bill language redo the core staffing formula related to SC's

Implementation of the rate study NOW, and reform of regional center core staffing formula to give service coordinators a professional wage so they can do their jobs. You cannot serve the community with a caseload of 70 plus

Education to individuals as to what is out there

awareness to home programs

make it a little more open to qualify for services.

I.D.K. (I don't know)

accessibility for people with I/DD

Education about these services and qualifications

Informing the community about the programs and what they do. People can start their own businesses, especially families who already have family member with a disability.

Local and statewide joint trainings and workshops.

creating more programs for mental health treatment of DD population

I need it

Social events for everyone and to be included in them.

provided or make sure more Psychiatric take medical

more doctors, take medicine

universal healthcare, increase SSI and HUD housing. Increase IHSS so a person is fully covered
685. workshops, maybe?
686. I am not sure, I do know that the mobile dental is a good idea. Maybe a mobile podiatrist or eye doctor ..
687. Should allow more hours of care
688. same as above
689. training for people, services, improve attitudes
690. More parks in community
691. Longer transportation services, options about churches, medical professionals, etc.
692. DOR plus policies of the state.
693. Training for care providers on how to navigate medi care, Medicaid, eligible client, training on IHSS hours, how Alta calculated.
694. Day Programs
695. Sports, more volunteering
696. Group meetings. Places where children with disabilities can connect
697. group speech therapy programs for the age 0-3 population and age 4-5 preschool population
698. Funds to support staff wages & benefits; outdoor activities; transportation training; personal choice community activities.
699. We don't have a cohesive plan or any outcomes. No one gets any help they need.
700. Collaboration with County Mental Health to ensure that people with disabilities can access behavioral health services and aren't turned away based on their disability
701. More special event access within the community for disabled.
702. Identifying additional supports and informing consumers of their availability.
703. Groups, Training programs, Circles of intimacy being taught in a wider variety of settings, teaching a wider range of social tools for a longer time, educating the public more about what a "disability" is and can look like
704. advocate for living wages for direct care staff.
705. In sports programs in which children can develop.
706. Medical areas and areas of social activities.
707. He wants to be taught HOW to do things, not have them just done for him.
708. Promote / give incentives to local communities (Church, gym, community center, library, museum ...) to provide volunteer opportunities and help community /business people to develop a training plan for people with special needs.

709. Pre employment training

710. Place for them to come as needed without and fees.

711. maybe more opportunities to do things myself

712. go to parks, vacations

713. More community events that can serve our population.

714. social groups in the community

715. Home visit, personalized activities to embrace the culture of each individual

716. Dance, music, Arts, they are very expensive activities,

717. more info on all services available to children with disabilities

718. Hosting talks and events featuring people in those fields who would be able to answer any questions to the public

719. Social immersion/vocational training

720. interactive programs

721. Social skills programs for our kids

722. Support legislation

723. Supported living services - increase the living wage so helpers stay with me longer.

724. would like to know how to navigate the different agencies

725. Inviting external agencies/agency representatives to provide in service/meetings to go over general information about their services.

726. Reach out to the DHCS to highlight healthcare service denials due to accommodation failures and 2. Collaborate with other arms of HHS to adopt common care staff regulations, so that how a care staff can assist is NOT dependent on what entity is paying them at that moment in time (this will soon become a bigger problem given the onset of EVV);

727. Mental health support

728. Parental information regarding disability, therapy support

729. community outreach to interact with other parents

730. Helping support families with Medical and Medicare.
731. I can't get unemployment or social security once my child no longer is alive or once hospitalized for more than a few weeks. IHSS law doesn't allow a parent to have taxes taken out for social security. I can become homeless if there is no other income besides my child SSI or my IHSS through him.

732. Outreach, BBQ’s, healthy activities through YMCA or similar

733. sports, dances, etc.

734. SSI training for parents, IHSS and, DOR, Job readiness skills from school and Regional center

735. NA

736. Social skills and making friends outings.

737. Advocacy for continued funding of these services. More statistics and stories that exemplify the need for the services brought to state and federal officials, and statistics showing the efforts to eliminate inefficiency, fraud, or other wasteful spending of taxpayers’ dollars be published and distributed to powers that be.

738. SSI and jobs not affecting benefits.

739. Provide a phone line expert for help in these areas.

740. Community gardens, maybe a community flea market,

741. These supports should include learning and recreational activities, respite care, and support with finding IHSS providers

742. Picnic

743. Promoting relationships and open minds. Building the community capabilities and finding opportunities to honor the gifts individuals with disabilities bring to the community. Encouraging welcome within the community.

744. Again stronger partnerships. The whole process is very frustrating and difficult.

745. agencies follow through with promised services

746. continued workshop employment regional center want my daughter to go from full day workshop to ten hours of community integration

747. Case manager should provide information available to parents

748. IHSS

749. Audit Regional Center (and/or replace them) with a complete change to focus on outcomes and viable planning vs. the status quo.

750. more inclusive support and clubs, classes to help the community understand these are your neighbors, sons and daughters as well as real people who love and care like you do.
751. Independent living skills programs that offer a range of services. More community outings
752. working together
753. training, new ideas???
754. IHSS is critical to living with dignity and some independence. The respite care for families is crucial for parents like me to maintain their mental health.
755. IHSS/Medical & Medicare
756. State should do everything.
757. Creative ways to obtain care in rural areas
758. make our service providers a priority.
759. Determine what are the true values we want to fund
760. advocate at federal level for SSI increases.
761. Help people find jobs to make more money
762. SCDD should focus on creating resource coordinators specifically to navigate community supports.
763. help get incentives for building
764. Dedicated support in resolving coverage issues with the various authorities including Medi-Cal and Medicare.
765. Supporting asset based community development.
766. better access to information for medical and programs.
767. picking up trash.
768. Senior programs
769. Organization or community that will embrace them for society integration (e.g. transportation, accessibility, more bus routes or transportation services)
770. Guaranteed health care
771. Community building event
772. Career Opportunities.
773. Resources to support independence with goal being phase out.
774. Ensuring individuals and families are all aware of and have access to the supports which they are entitled and eligible for.
775. Job that pay higher incentives
776. Higher paid supports to allow community access
777. LE, schools provide needed referrals.
778. Help with benefits, housing, medical.
779. Trainings in which IHSS workers are more informed about the disability community
780. How providers can advocate when they know what to be advocating for.
781. Just give us more money
782. Continued IHSS support
783. Research, document, and report on the current service levels/programs of each of the supports being provided, what are the gaps and how do these impact the consumers? Advocate for changes; identify what services are lacking, and can be developed (or improved) for DD-Adults, esp. for consumers w/ Classic Autism.
784. I’m not sure, but I think social workers treat parents like they are trying to defraud the system for taking care of their disabled children.
785. Adult social groups
786. social get togethers
787. Have the powers that be set realistic standards by listing the actual cost of services and develop that meets these goals.
788. Encourage community organization to make events inclusive and integrated!
789. Strong support for Charter Schools and home-schooling is extremely important. This allows for the best use of additional formal and informal community supports to thrive. Continued support of organizations such as Special Olympics, Warmline, FEAT and Alta-Regional are extremely important as they help families learn about the laws, provide a community of support and offer numerous services to navigate the over-complex IEP process. Streamlining and simplification of the IEP laws, more support and funding for IEP services, simple training of school Program Specialist to actively inform parents of all of their choices and options would help. The current atmosphere is that too many schools are trying to minimize the IEP support to save money and then parents are trying to obtain the best education and services for their children, so the agendas are not truly compatible.
790. Not sure.
791. Having a speaker come to a group session to be about how to navigate the insurance network
792. oversight and abuse prevention for people not living in licensed homes
793. open forums
Educating the community and providers in the why and how.

Coinciding and treatment

Nonprofit / community involvement, job fairs, employment engagements.

increase hours for clients

Sporting Equipment and resources.

Provide funding to families/agencies/vendors to access support individuals' independence and success

On-going education provided to families on various supports they have in the community and how to access these supports.

different focus on the type of disability each person has as well as help with mental illness.

training on the laws that impact IHSS, SSI, Medi-Cal Etc.

Vocational, recreational, housing...

the only other activity for clients is senior centers, but sometimes these centers are not client friendly so incorporate activities within the senior centers to include clients

Help engage the disability community to be more active in their community and day-to-day life.

Needs more workshops.

Have more faith-based activities

Finding ways for volunteers to help support care homes (having extra hands providing extra emotional support (e.g. foster grandparent program as an example).

Explore feasibility of integration of IHSS services especially clients receiving protective supervision, into regional center. Having 2 systems is a duplication of services and hurts continuity of care for DD clients. Explore if putting IHSS hours under the regional center supervision would save the state money and improve quality of care

Helping to find housing, apply and interview for jobs, set up bank accounts, family planning, etc.

District Attorney using Warren Webber as Fraud investigator on IHSS cases without fraud suspected.

Support to get 1 on 1s

possible expansion of these benefits/rate increases
814. More community resources in the area of after care when persons served can't stay at home by themselves, but the parents work full time, as well as social/recreational resources

815. Knowledge of how these service agencies work, what their criteria is for qualifying, and what services they offer

816. Ways to participate with clubs, how to enjoy holidays other than with family........

817. Not sure, maybe potlucks, neighborhood events, volunteer opportunities

818. Continue supporting the program

819. health training.

820. Again, education about rights and RC services for the adult population. No one knows what their rights are and some are too lazy to dig for the information themselves.

821. But the clients suffer for lack of knowledge. Parents need to know the power of the IPP and what the Lantern act says about what their loved one can obtain.

822. educational activities.

823. Recruitment of quality staff, raising pay for support, and awareness of the impact support has on the lives of disabled

824. Community activities to teach the community our differences and to invite them to volunteer to participate in public meetings.

825. quality supports

826. Police interaction scenarios to get experience.

827. Child care and development.

828. I would like to at least start with some training for me, so I can handle day-to-day life with my adult child, it's currently not good. But the RC has provided nothing for over a year.

829. Hobbies, nature walks, whatever works for their different environs, rural, urban, suburban.

830. Anything that can improve access to care/services

831. Social connected activities. Awareness of community supports.

832. Educate the community about it.

833. Informing families of what is available to provide a better quality of life for their loved one.

834. mixed social events with typical peers
835. as above
836. there are great services available already,
837. More community based support groups, activities, etc.
838. Cooking
839. Sports, art
840. Art and outdoor activities
841. More hours for workers and add sections for miscellaneous tasks
842. Strong cultural community in town. Many of them have their own skills that they know how to assist in their own population to build a strong community. There are number of immigration confuse what wrong and right to follow.
843. innovative ideas

Spanish Responses (Translation)

844. Continue learning more about the Regional Center and other options for adult life
845. Also creating more resources for young adults in wheelchairs, almost none.
846. Make it easier and faster to have therapies outside and inside the home
847. That there is a support that can help clients to obtain supports and services in the community and assistance to help with application processes.
848. Social and recreational inclusion
849. Transitions to adult life
850. Work area
851. Self-advocacy
852. Giving information, workshops.
853. How would it be good to promote a law render accounts transparent, perhaps putting the information clear online for everyone and based on that
854. In the area of support formal and informal in the community
855. Parent trainings
856. In education, CR, community. What does one of these areas offer?
857. Give more information about what kind of services are coming to the community.
858. Top information about the stable aid
859. In more integration and preparation services so that they work and feel useful and help them with their over-esteem.

860. How can people appeal when they are immigrants

861. Socialize

862. For my son he needs independence and security.

863. Informative workshops in Spanish

864. Academic activities the basic, since our children and adults are unaware of the essential.

865. Classes in the community

866. In providing us with more information about the regional center, MediCal, Medicare, and services they can provide.

867. In giving accurate and understandable information

868. To help more with CR process and for the life of the client of said center

869. I believe that the Regional Center and access to services and that the coordinators are more supportive for families and are not so difficult with families

870. Helping parents by giving them the knowledge of how to access generic services that their loved ones may need

871. MediCal, MediCare, and IHSS

872. C.R. and Medical

873. In everything that is necessary for everyone

874. Services for RCEB clients

875. Recreations for children

876. In earning more resources for independence

877. More workshops

878. You find that the surveys are not very important to the parents

879. Everywhere in region and support

880. Community support and services that impact the lives of people with disabilities and their families

881. Be able and trained to know what is still needed.

882. With information and support when we don't know how to navigate the system.

883. Serve educating families
884. That it is state work to reduce bureaucracy and investigate complaints of child parents
885. Check that they are complying with the agreements to the needs
886. Parent education
887. IHSS and Medical
888. For medical, they do not provide training on how to get rid of the medical waiver by the regional center
889. In the community there are no activities for children with special needs
890. If you could please how to fill out and the application
891. Generic service
892. Give informative workshops
893. In that we give more respect to families of people with disabilities from coordinators and supervisions and that they are provided with what they need without disrespect.
894. At IHSS, medi-cal and medicare.
895. Maybe where you can develop your skills and support your needs
896. Let the state work to rediscover the bureaucracy and investigate the complaints of the parents.
897. Help to get the hours we need from IHSS.
898. Information workshops on the different supports for people with different abilities
899. Workshops of IHSS, SSI, Regional Center, MediCal and more. Information for us to educate ourselves and oblige my parents.
900. Work to have them removed
901. How to navigate the regional center and how to learn what other supports are in my city
902. Assist parents and clients to obtain services
903. In supporting children and parents
904. Make him an income for the SS
905. In which the offices are compassionate and do not treat you as a burden
906. Provide trainings
907. In the integration of services in the community.
908. How to get these services, how to maintain the services
909. Giving us more information
910. Medical services training
911. Also include SSI and tax information.
912. More talks or brochures about this
913. What do they say about the medical and the IHSS, how soon do they change the system and are a little complicated
914. Educational workshop
915. Trainings
916. Educate the community and employees of three agencies
917. Eb Support groups and training in the community
918. Training
919. Medical insurance
920. Make it an income for ss
921. In which the offices are compassionate and do not treat you as a burden
922. Provide trainings
923. Information workshops
924. Support people, persuade families
925. How can we politely advocate for our children so that they are included, and accepted without discrimination?
926. Give more educational workshops on the different disabilities and share them everywhere. E thus prepares how to treat a disabled person.
927. Seek BCBA and ADA services for our children in being mental health.
928. Public places (clinics, libraries, churches, police, etc.) do not know how to treat people with special needs and more difficult when they are already adults.
929. As much as possible the more we know the more we can take advantage of resources
930. Services for adolescents and adults CR rehabilitation office and costumes
931. Sports, volunteering, and primarily IHSS support.
932. Information about things that can help like potatoes to help our children 4 best rights.
933. That they promote more information so that people obtain their medical
934. That the staff be educated. Workshops
935. Continue educating us and gathering parents to help other parents.
936. More supervision/training for RC coordinators
937. Review the police services about access and info
938. Because in many
939. Workshops, testimonies, information services/mental health community services
940. More help for a parent who doesn't know much about help or therapy for our children.
941. Medical generic services.
942. In that they help more to the families of low income to be able to obtain, more services.
943. More than anything in being stricter with the agencies that provide these services. Sometimes therapists do not put passion in their work
944. And they only do it out of necessity
945. Have more talks about services in different languages and have questions answered in detail.
946. Parent education
947. Be closer to us
948. What services are there in the community?

Japanese Responses (Translation)

949. An activity that encourages as many people as possible to understand what is called a disability, and recognizes that all human beings are equal, regardless of whether they have a disability, and that even if they have a disability, they can always do better than others.
950. All services they should.
951. Easy access to information
952. I would like to know more about government services (including SSA / SSI).
953. I want more activities in the community.