



State Council on Developmental Disabilities

State Plan Committee

2022 – 2026 State Plan Development

Goal Development Worksheets

(Parts 1 & 2)

Health & Well-Being

1. **What about this topic was most important to survey respondents?**
 - A. Everyone wants health care and they want to be safe, emotionally and physically. A lot of people stated it is a human right to have health care.
 - B. Health is one of the top priorities for a lot of people. Without good health care and being healthy, the alternative is not so good.
 - C. Comment number 5 provides a great summary of many of the comments in this section: In order for any of the other programs to be a benefit one must have good health and well-being. Also, comment 2 is lens into this category: Physical and Mental Health are crucial to a quality life.
 - D. The major themes that emerged in Health and Well-Being are: the critical importance of good health; availability/access; cost of care and medicines; stress on SA, FA; Need for family care person to be healthy; Need more providers that understand the ID/DD community; Senior Health issues; quality health insurance; dental access and coverage.
 - E. Some other poignant comments that reflect the overall picture:
 - F. #1175. *We are among the most at risk for assault, exploitation and medical neglect/malpractice.*
 - G. Comments #1288 and 1300 are lengthy and need to be discussed.
 - H. Comment #583 Physical and mental health need to be optimal and stable for anyone to live a meaningful life with job, education, etc.
 - I. Quality of Life (QOL) is tied to health
 - J. Physical & mental health gives the ability to do anything (work, social, daily activities)
 - K. Health outcomes tied to ability to communicate
 - L. Access to health services is needed across the lifespan
 - M. Health care must be affordable
 - N. Health care for caregivers must be accessible & affordable
 - O. It was clear that without good/positive health, nothing else really matters. Respondents seemed pretty versed on what is needed to stay or become healthy (e.g., exercising, seeing dentist, visiting their physician, etc.). In many cases, health was equated to happiness.

2. ***What about this topic is most important to you, as a Council member?***

- A. Being healthy is very important and it hurts when I see people dying from lack of health care. I think emotional well-being is so important to help curb suicide and depression.
- B. In answering this question, I feel it is critically important to always keep our mission in mind: ***The Council advocates, promotes and implements policies and practices that achieve self-determination, independence, productivity and inclusion in all aspects of community life for Californians with developmental disabilities and their families.***
- C. **As a member of SCDD I view it as my role to first listen and take seriously all the comments in question 1 and then to assess what is in our mission, capacity and scope of responsibility.**
- D. The comments that seem to be most relevant and compelling ,and capture many of the other comments, for our mission are: Comment #4 – Seminars (This is expressed in many ways throughout the document), which fits into our Education goal; #183 – Communication about services available; #226 – MediCal – Advocacy; #269 -Training of health care professionals; #343 – advocating for prescription drug prices; #352/932 – database of health care providers. Great idea – is that in our purview? #433 – Training and Support for Providers; #655– More information about services available; #679 – Advocacy and Awareness– about wellness; #905 (very interesting) – access to activities.
- E. There is so much here, and I am confident that the committee will sort this out in our process.
- F. Health care access and affordability for individuals, families, and caregivers
- G. It was mentioned a few times, and I concur, that the medical prescriptions and equipment, and expenses associated with healthy living for someone with I/DDs is often mistaken as “the same” as the needs for everyone else.

Housing

1. ***What about this topic was most important to survey respondents?***

- A.** Most people voiced there was a lack of affordable house for people with DD. Living on little to no income does not allow people independence and choices when they only have SSI. People who do not have a family or advocate could easily become homeless.
- B.** The overall summary of this topic can be seen in the following responses:
- C.** #1 *Lack of affordable housing for adults with special needs.*
- D.** #13 *The unaffordable nature of housing affects individuals, families, staff and service providers*
- E.** Comment #151 seems to explain many of the shorter comments: *Disabled people...*
- F.** My Q – is this an accurate assessment of the situation? Same Q for numbers 53 and 320 about Section 8.
- G.** **Key takeaways: The cost of housing in CA; Accessible housing; Housing needs to be safe; concern for elderly DD/ID; Impact of fires in several communities; Housing needs to be near services; Housing allows for independence; Specialized housing for medically fragile people; Fear of homelessness.**
- H.** The Housing crises impacts everyone: People with DD/ID; caretakers; families; service providers – everyone.
- I.** Q – How many ID/DD are homeless?
- J.** Q – Is there statistical information about the housing situation for the DD/ID community?
- K.** Comment #1346: *It seems to be the biggest issue for many of our consumers.*
- L.** Affordability
- M.** Limited stock!
- N.** No availability of current stock
- O.** Choices of where to live & with whom
- P.** Needed to access other services
- Q.** Safe and affordable living spaces. Often, the safety becomes secondary or compromised to merely having some place to live.

2. ***What about this topic is most important to you, as a Council member?***

- A. I have a section 8 voucher, however I can only live with my mom because I cannot find housing that accepts the voucher. Even the apartments take them; their waitlist is closed and could take decades to get an apartment in the community I have grown up with.
- B. What will happen to me if my mom dies before me?
- C. In answering this question, I feel it is critically important to always keep our mission in mind: ***The Council advocates, promotes and implements policies and practices that achieve self-determination, independence, productivity and inclusion in all aspects of community life for Californians with developmental disabilities and their families.***
- D. **As a member of SCDD I view it as my role to first listen and take seriously all the comments in question 1 and then to assess what is in our mission, capacity and scope of responsibility.**
- E. Important items for SCDD – **Advocacy** for affordable housing;
- F. **Education:** Comment #16, *Primers for people who know nothing, training for people how to become advocates.*
- G. Response #42: *Advocacy – Increase Availability of facts to help: 1) Develop more low and very low income housing 2) Funds for transitional housing, security deposit and emergency funds to use to prevent housing.*
- H. Q's: What is the current situation of Section 8 housing?
- I. Do we have a role in enforcing the Lanterman Act?
- J. **Most important:** Advocacy for affordable housing, Educate people on what might be available to them; Materials/ Resources on how people can best apply for programs and resources to help affordability; Resource Center – of Statewide/regional groups that especially focus on the DD/ID communities; Create coalitions with other vulnerable groups – the poor, vets, anyone group that cannot access housing.
- K. Housing security accross the lifespan.
- L. Subsidized housing programs, specifically designed for persons w/ intellectual disabilities is essential. I didn't specifically see it listed among the comments, but, I think more living communities are beneficial. I'm referring to self-contained living communities where they have grocery options, parks, etc. that are built in such a way that is conducive for multiple physical and intellectual persons - yet, not isolating.

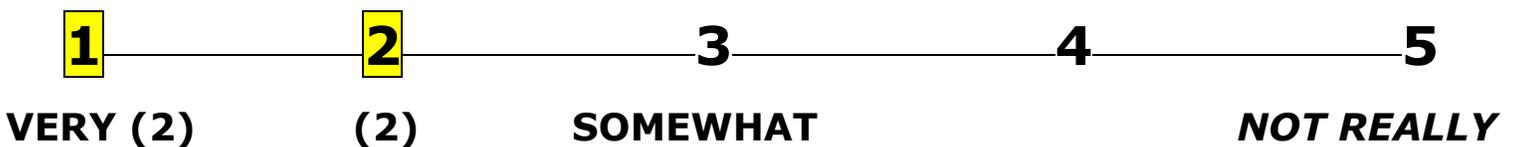
3. **Please check any related boxes if you believe that 1 or more other topics should be included (in combination) with Housing as a (combined) goal area:**

- | | |
|--|---|
| <input checked="" type="checkbox"/> Health & Well-being | <input checked="" type="checkbox"/> Early Intervention |
| <input checked="" type="checkbox"/> Housing (4) | <input checked="" type="checkbox"/> Transportation (3) |
| <input checked="" type="checkbox"/> Education | <input checked="" type="checkbox"/> Recreation/Social |
| <input checked="" type="checkbox"/> Employment | <input checked="" type="checkbox"/> Child Care |
| <input checked="" type="checkbox"/> Formal/Informal Community Supports (3) | <input checked="" type="checkbox"/> Self-Advocacy (<i>Required</i>) (2) |
| <input checked="" type="checkbox"/> Quality Assurance | <input type="checkbox"/> Other _____ |

4. **Explain why you do (or do not) want to combine this topic with 1 or more other topic areas:**

- A. Housing is a big enough issues on it's own – no combining!
- B. It is clear that having independent or group housing that is affordable for the DD/ID communities is critical for everything. One cannot be homeless and be healthy. To have a sense of self-esteem, one must feel safe.
- C. Both housing and health are essential. They are inextricably linked.
- D. Without housing cannot stay healthy
- E. Without housing cannot register for support from other service systems
- F. Without housing cannot use paratransit effectively because of wait times or no shows
- G. Where one lives must be able to connect to other communities (transportation). Transportation can be mass transit or a local group of drivers (e.g., Uber/Lyft, or small vanpool companies).

5. **How important is this goal area? (Please circle OR highlight your choice)**



Education

1. ***What about this topic was most important to survey respondents?***

- A.** Education will prepare anyone to have a more functional life when they get to the adult life. Everyone should get the chance of learning and being independent.
- B.** *Note SA rank this 4th with the differential being 3.7 for first place and 4.5 for fourth. I view less than .5 as not really being statistically significant. Is that accurate?
- C. **General Education.**** #10 *Proper education is the foundation of for a successful adult life.* This is stated in many different ways. However, there seems to be a variety of meanings of education.
- D. **Skills to navigate system:**** #11 *Because we need the tools to request the services that are needed*
- E. **Life Skills**** #39. *Ability to learn life skills* – this is also reflected in many others and really seems to deal with how to handle money, living independently, etc. (#219, 720)
- F.** Most important: General Education, Ability to navigate system; Life skills; schools offering appropriate services (#70); Education for parents (#91); Parental concern about children being educated; Vocational Education (#488); Inclusiveness; Special Education; Resources, Understanding Rights (425); How to work better with people with DD/ID (#1069); post high school educational opportunities(#1376); Different needs: (#195)
- G.** Information Q's: Is #192 an accurate assessment? Can we get more information on this?
- H.** #237 is of course so true. How much are educational programs for the ID/DD community more underfunded?
- I.** General statement about education #466: *Education provides self-esteem, friendship, how to self-advocate, self-help, critical thinking, social skills.*
- J.** Education is basis for employment
- K.** IEP training
- L.** Need for college opportunities
- M.** Education is needed for parents and aids to support children
- N.** This was the most difficult category and feedback seemed to be all over the place: Well trained and educated school staff; equal access; external education opportunities; therapies; preparation for job readiness; parental knowledge of the educational system; IEP challenges

2. ***What about this topic is most important to you, as a Council member?***

- A. Education is everything and it is a right for all human beings. Not that long ago title nine was approved so women could be educated, then we had the Lanterman Act for people with disabilities, what will be next? Truly, full access to education? There is discrimination against people with disabilities and services need to be consistent and dispersed equitably throughout the State. Everyone should be receiving services to access education, "Everyone can and will learn".
- B. What strikes me about this category is that it presents as much more complex than either health or housing. There are three major categories: general education and its importance; life skills that help navigate the system and to live independently and vocational training. As a member of the SCDD I would like more information about 192, 237, #106 on page 97 – the Donahoe Act, #123, Pg. 97 Issues of legality; Issues raised in 343 and 344 on page 107; Is there a database like mentioned in #622; AB705 and cutting of resources - #1312, page 73. It would be great to have summaries of these situations for our discussion. Thank you.
- C. **Great need for educational advocacy** – funding, access, individualized programs;
- D. **Education:** Parent support, Teacher training, etc. #10 (page 93)
- E. **List of educational programs** starting in preschool that are friendly to ID/DD community (19, page 93)
- F. **Education transition** between high school and education #230, pg. 102
- G. **Accessibility**- #527, page 114; Although this is an aspirational goal, what grade would we currently give ourselves on how we are doing and what is a realistic goal? In what way can the SCDD have an impact here?
- H. **Special Education** – page 568 – Workshops for parents and advocates on IEP
- I. IEP training
- J. Raise the standards for FAPE. Education in this country always talks a good game, but takes a backseat in real life. We never seem to pour all of the resources that are needed in this area. Which is why I think it suffers the most. It feels like an insurmountable task to achieve (FAPE), so it frustrates people across the board - parents, educators, and legislators.

Employment

1. ***What about this topic was most important to survey respondents?***
 - A. Most of the people surveyed felt employment was important because they want to make money for: living, housing, food, entertainment, socialization, being a part of a working community.
 - B. If people with IDD want to work, then they should be able to!
 - C. *Note: SA rank this #1, with housing and health being very close behind. FA rank this number 3 but very close to top 2 Health and Housing.
 - D. **Key issues for respondents:** Work provides purpose #205; Financial Security; Step towards independence; Concern about children; help with resumes and how to interview #56; Need to incentivize companies to hire DD/ID; I want to work; Helping people set realistic job goals; more job opportunities; Social connection;
 - E. Some overarching and insightful comments to discuss: #130, #260; #592; #1595, page 73;
 - F. #637 *Job, money is the foundation for good/inclusive lives*
 - G. To have value in society
 - H. To be able to do something after finish high school
 - I. Not enough opportunities in any field other than this one
 - J. MONEY! The need to earn income was paramount. Many felt it also gave them "purpose" to be able to work and contribute to society in that way (as productive citizens). Oddly, there were innumerable references to "sons", and issues surrounding employment for them. Not sure if the expectation is there more for males than females, or if there are simply more males with the I/DD diagnosis. The other theme was the need for increased job opportunities (job scarcity)

2. *What about this topic is most important to you, as a Council member?*

- A.** Money is not every thing; it will not always buy you what you need. If there is no housing available, it does no matter if you have money. I think employment is great if you are doing a job that is meaningful and you are passionate about.
- B. *As a member of SCDD I view it as my role to first listen and take seriously all the comments in question 1 and then to assess what is in our mission, capacity and scope of responsibility.***
- C.** Q Would like to know more about comment #436, page 22.
- D.** Q Would like to see statistics regarding unemployment rate for DD/ID, #715, page 35
- E.** Q Resources - #746, page 37
- F. Q** Is #350 accurate about SCDD, see page 99.
- G. *Important to me as SCDD***
- H.** Advocacy – Job opportunities, pay, accommodations, protection from work discrimination,
- I.** Funding for job preparation programs;
- J.** Education – See comment #1073, page 129
- K.** Resource Fairs
- L.** Educating potential Employers – Comment #1104; page 131.
- M.** Better vocational training to prepare people for jobs
- N.** Can PRIDE be replicated, #948, pg. 124
- O.** Finding unique ways to develop or match skills with an area of interest or talent.
- P.** A part of me feels like it’s more of a perk for society than the individual with I/DD. Engagement through employment has the natural capacity to bridge some of the uncomfortableness that I think many folks feel (but don’t admit to). It puts people with I/DD in regular spaces that “others” frequent (for shopping, business exchanges, etc.)

Formal/Informal Community Support

1. *What about this topic was most important to survey respondents?*

- A.** Most important was IHSS and Medical. Most people said it was important, however IHSS pays so low, it is hard to get good consistent people. Also, it is extremely important for our IDD population to have access to programs and social activities. However, many times there is a long waitlist and success is sometimes not available.
- B.** Most important was IHSS and Medical. Most people said it was important, however IHSS pays so low, it is hard to get good consistent people. Also, it is extremely important for our IDD population to have access to programs and social activities. However, many times there is a long waitlist and success is sometimes not available.
- C.** Q* On the questionnaires were the categories described or just stated as we see them?
- D.** If they had descriptions it would be helpful to see.
- E.** In my reading of this document it seems like there were many ways of answering this question. A lot of the responses seem to belong in Health or Education.
- F.** My understanding is that **formal support** refers mainly to IHSS as well as Medi-Cal, which a lot of comments referred to. If I am correct that is what is covered by this description on the DDS website? "The Home and Community-Based Services for the Developmentally Disabled (HCBS-DD) Waiver is administered by the California Department of Developmental Services (DDS) who will authorize home and community-based services for developmentally disabled persons who are Regional Center consumers. Twenty-one regional centers throughout California purchase and coordinate services and supports for individuals with developmental disabilities. The Waiver services make it possible for consumers to live in the community instead of an Intermediate Care Facility for the developmentally disabled or a State Developmental Center. The DD Waiver is currently the largest HCBS waiver in California as well as the nation."
- G.** Q: Does **Informal support** refer to everything that the above does not cover/describe? Recreational, Social, Arts? Does informal just refer to State sponsored activities or also those offered by non-profits?
- H.** **Major concerns:** Understanding all that is available; Education about available resources so that people have the skills to self-advocate; Having access's to activities; Transition support after high school; Finding caregivers and improving their salaries; non-profit organizations like Special Olympics, Warmline and FEAT,

etc. Comment #644 page 34; Identifying and accessing Resources, Comment #728, page 38; Respite care;

- I.** IHSS, MediCare, MediCal, and other services are very important b/c don't get enough through Regional Center
- J.** Need more services than just parents, school, & Regional Center
- K.** w/o these services cannot be independent adults
- L.** This was another topic that had a wide range of responses. People mentioned federal/state resources and social services (like IHSS, MediCal, and SSI), along with recreational activities within their neighborhoods – how to integrate friends (inclusion). Families as a household unit seemed to need help (from regional centers; more financial support; more overall health services).

2. ***What about this topic is most important to you, as a Council member?***

- A. Making sure I am receiving all the services I qualify for. . . but not only on paper. So many times I receive services . . . there is no one or the person is not qualified for the position and it is a waster of my time and taxpayers money.
- B. **As a member of SCDD I view it as my role to first listen and take seriously all the comments in question 1 and then to assess what is in our mission, capacity and scope of responsibility.**
- C. **Resource sharing**, Page 45-47?; Comment #1014, pg.51, Q does that complete list exist?; #7;
- D. **Education** - #275, page 76; re: Self-Advocacy – Comment #325, page 78, #329, page 79; #549m page 88 – “helping to connect the dots.”
- E. **Advocacy** – to improve IHSS; many comments – see #1019, page 51; to strengthen Medi-Cal;
- F. **Ensuring** that social events are available, Fund them? #397, page 81;
- G. **Q** Regarding Comment #456, important to discuss – what have we done well, what could we improve that is in our purview?
- H. **Q** – Comment #789, page 98 – what about this is our role as SCDD?
- I. **Comment #15** – *I would like to get a booklet of information put together, which could then be given out showing information a special needs person and the family or caregiver could use.* Comment #139 also states this well.
- J. I would add to this that teachers, health professionals, anyone who comes in contact with people from the DD/ID community should have this. This seems like a key part of both education and resource sharing.
- K. Must have braided services to create an effective system of supports
- L. I got the sense that many people didn’t know specifically what to ask for in terms of what they needed, except that they knew their current situation wasn’t enough. That leads me to wonder if outreach and the promotion of activities/events are reaching the majority of the target population. Because sources change, marketing is critical.

Quality Assurance

1. ***What about this topic was most important to survey respondents?***

- A.** Many people answered the question to me “quality of life” and those insights really connect to all the other categories/goals we are reviewing. Comment #233 on page 46 captures many of the other thoughts: **We all deserve to live a healthy, long life. We are living longer! But with what quality of life?**
- B.** The definition that was discussed in the meeting might be summarized as follows:
Quality assurance means developing operational controls to ensure that the results match the desired outcomes.
- C.** Several comments do refer to that definition of QA including #12 – **Need for more regional staff to do this**; #33 – **Management of those who provide Direct Care**; #100, **Need for better training**; #278 – **“The entire system needs quality oversight”**; **Need for more funding to do QA (281)**; #333 **“All vendors need to be following policies/procedures to ensure quality levels of care..”**;
- D.** Quality Assurance is important for an excellent, happy life. There needs to be accountability for all services and the Regional Center. Quality assurance does not seem to be happening in the developmental community.
- E.** There are programs that are not serving people is I/DD, but still are being funded.
- F.** The need to improve “quality of life” was a recurring theme; QoL is essential
- G.** “Quality matters” (x2)
- H.** In over 2 decades, ADA is still not enforced sufficiently
- I.** No one is really looking at what’s really going on; oversight (of providers and services) is necessary; not enough is being done (to ensure resources are available)
- J.** Regional Centers. Need to do more; they need more funding; workers are stretched thin (over-loaded)
- K.** Wanting or living a “happy life” was written a several times
- L.** People are very confused about the difference between this and Quality of Life

2. *What about this topic is most important to you, as a Council member?*

- A.** Getting better **accountability for all of our work** (stated very well in Comment #24, Page 38.
- B. Educating** the general public on better ways to interact with self-advocates #57
- C. Increase Funding to Regional Centers** to help ensure QA- #71, page 40
- D. Advocate for better funding for service providers to help promote a better service delivery** – Comment #412, page 54.
- E. Funding annual reviews** Comment #460; page 56
- F.** I would like to see better quality assurance for transportation and ILS services. I would like service providers to be enthusiastic and caring about their job and the people they work with. They also need better training to deliver good services.
- G.** Though I'm typically not in favor of "big brother" leaning over your shoulder to make sure you're doing a good job, BUT I would like to see more support around ADA compliance. That doesn't necessarily mean fining folks/agencies that are not in compliance, however, it could mean more instructive training opportunities made available so that ADA regs stay fresh on everyone's mind, and not something that occasionally shows up as a problem via a law suit.
- H.** I want to make sure that the services being received are effective, efficient, evidence based, and produce positive outcomes for members of our community.

3. **Please check any related boxes if you believe that 1 or more other topics should be included (in combination) with Quality Assurance as a (combined) goal area:**

Health & Well-being (2)

Housing

Education (2)

Employment (2)

Formal/Informal Community Supports (2)

Quality Assurance (4)

Early Intervention (2)

Transportation

Recreation/Social

Child Care

Self-Advocacy (*Required*)

Other _____

4. **Explain why you do (or do not) want to combine this topic with 1 or more other topic areas:**

- A. QA is a part of every other goal. No need to have on its own as it critical to all the other areas.
- B. I would not combine because I find this to be very important and hugely lacking in California.
- C. Maximizing QA will take community involvement and potentially community resources to fulfill its (QA's) intended goal/purpose.
- D. Health care services have to be consistent and easily accessible and understandable
- E. Education services need to more monitored and consistent while individualized
- F. Early intervention needs to be a launching for everyone
- G. Employment programs have to scaled and offer similar supports no matter where you are

5. **How important is this goal area? (Please circle OR highlight your choice)**

1

2

3

4

5

VERY

(2)

SOMEWHAT

NOT REALLY

A. It is very important but should be integrated into all other goals

Early Intervention

1. *What about this topic was most important to survey respondents?*

- A.** I found the responses to this goal to be the most unified in response, this summary reflects many comments: **Diagnosing and providing services to children with DD/ID is critical and have a life-long impact.**
- B.** Although very low ranking for SA and FA – it is still considered very important.
- C. Important issues: Early Diagnosis; Information for Parents about EI; Getting into System; Accessing services.**
- D.** Seems to be a lot more response from Spanish speakers on this topic; they conform with the English speakers in articulating the needs.
- E.** People felt early intervention is very important for the health and well being of all people with I/DD.
- F.** Their needs to be better communication and access to programs, especially with the low-income population
- G.** Important for parents to understand the needs of their children so that they can better help their kids; some families still don't know about early intervention
- H.** "We need to do more"; "0-3 are the most vulnerable"
- I.** "Not enough funding to adequately address youth issues that could have been prevented at an early age; life-saving preventative help prevents more disruptive behaviors; helping children with disabilities at an early stage increases the chances of them obtaining more opportunities and preventing injustices for others
- J.** EI services are critical and set up for better future outcomes
- K.** Help parents learn about disabilities early

2. *What about this topic is most important to you, as a Council member?*

- A. Education, Awareness Outreach** – stated well #35, page 50: Workshops on funding and services for early intervention. Families don't know what to do when a child is diagnosed.
- B.** What comes through here most clearly is the need for more information and awareness about EI for parents, medical professionals, teachers, everyone.
- C. Advocacy** for more services to the DD/ID community in the early years – given that they really have a lifelong impact.
- D.** I felt the responses did not have enough information for me to answer this question.
- E.** This is the most heart-wrenching category of them all. Reading the comments took me back to a painful place. “The beginning” was the hardest part of this developmental journey for me. There are more adults with I/DD so those numbers always appear higher, in my opinion, and that their needs are greater or more severe. Although the 0-3 population may be lower in numbers or volume of services rendered, so much more can be achieved later in life if the fundamental elements are strong.
- F.** Parents understanding child diagnosis so can adapt to support their child
- G.** Beginning interventions early for improved outcomes

3. **Please check any related boxes if you believe that 1 or more other topics should be included (in combination) with Early Intervention as a (combined) goal area:**

Health & Well-being (3)

Housing

Education (3)

Employment

Formal/Informal Community Supports (2)

Quality Assurance

Early Intervention (4)

Transportation

Recreation/Social (2)

Child Care (2)

Self-Advocacy (Required)

Other _____

4. **Explain why you do (or do not) want to combine this topic with 1 or more other topic areas:**

- A. I think it can be combined with Education, Health and Well-Being, as well as Employment.
- B. It belongs in these categories. I guess the only concern is that if EI falls to the bottom of these categories and not considered a priority.
- C. I think Early Intervention could be combined with Health and Well Being or Education.
- D. Both of these categories should start at birth, which is what early intervention is.
- E. Physical health and medical needs are so critical for babies and toddlers. Social outlets for parents and caregivers is necessary for sharing additional resources and offering emotional support so they can withstand all the newness of what they are dealing with; group interactions with 0-3 peer groups, is helpful/essential for the little ones as well (Rec & Social). Appropriate child care facilities and respite is a must (Child Care). The early years of educational learning sets the stage for later years (Education).
- F. If can learn to support health needs early will be able to improve outcomes as child ages
- G. If can begin basic things like Alphabet and number recognition can improve basic outcomes like name, address, phone recollection (safety information) or basic reading skills among those with more intellectual abilities

5. **How important is this goal area? (Please circle OR highlight your choice)**

1 _____ **2** _____ **3** _____ **4** _____ **5**

VERY (2)

SOMEWHAT

NOT REALLY

A. Note: It is very important but should be combined with others.

Transportation

1. ***What about this topic was most important to survey respondents?***
 - A. For SA, Transportation is ranked 8th, but very close to 6 and 7.
 - B. For FA, Transportation is ranked 9th.
 - C. Transportation is critical for any kind of independence. #69 **It is key to having control of my life and choices.** It is also summarized very well in #116: **The basic component of independence is transportation.**
 - D. **Concerns:** Hard to find quality transportation providers. This is essential for safety. The feeling is that most places in CA do not have great public transportation. Especially noted where the many problems in rural areas.
 - E. Issues with buses, Driving Companies, Cabs, Vans. Often unreliable and often people with ID/DD do not feel tolerated and understood.
 - F. **Transportation is critical for going to after school provider, medical appointments, work, college, Social Services, Recreational and Religious activities and any community program.**
 - G. Transportation is need before a job. With a way to get there, it does not matter.
 - H. People should have more choices and utilize Lyft or Uber at a discounted avoid an excess amount of time for passengers to spend on a route to their destination to accommodate other passengers and their business costs.
 - I. Not enough choices; options are limited
 - J. Safety is a concern
 - K. Access in rural areas is cumbersome
 - L. "Free" transportation was mentioned a few times
 - M. Need to have reliable, safe, and efficient transportation
 - N. Need to have more choices in providers, especially in rural areas
 - O. Need to get to job, school, grocery, doctor's appointments

2. *What about this topic is most important to you, as a Council member?*

- A.** It is very clear that transportation is essential for employment, health care, education and many other activities.
- B.** Educational Workshops: What is available and how to best utilize what is offered.
- C.** Advocacy: To improve the quality of services; to better fund options for the DD/ID community; To help providers in the transportation industry (public and private) understand how important this is area is for this community who for the most part is totally dependent on it; and if ever possible to increase transportation subsidies.
- D.** Comment # 264 (page 49); Lobby Uber/Lyft type entities to offer subsidized rates for people with special needs. Q Can State Agencies, like the SCDD do that with private companies?
- E.** Important to better supervise transportation services for quality assurance. Q Does any agency have that authority?
- F.** In the spirit of brainstorming – could retirees be enlisted to become drivers. Key issues would be making sure they are vetted and safe in every way.
- G.** Reddi-wheels is not a good model for me. It is always late, you have to call 24 hours ahead of time, and sometimes I am in the car for hours while they are dropping off other people. It is extremely unreliable. I have addressed my concerns directly, however nothing has changed. Just excuses!
- H.** Driving is not an option for many persons with I/DD and being reliant of transportation of some kind is their only way of getting around town; comment #357 – nothing can happen without reliable transportation; #380 – nothing is possible without better transportation
- I.** Basic public transportation could use enhancements, especially in rural communities, but also physical accessibility with wheelchairs and other devices/apparatuses
- J.** The cost of transportation is an issue for some
- K.** Letting people get around independently and safely
- L.** Having availability to get to necessary location (work, school, doctor)
- M.** Making it affordable, reliable

Recreation & Social

1. ***What about this topic was most important to survey respondents?***

- A. For both SA and FA, Recreation is at #7, significantly below the first six for SA.
- B. **Concerns and reasons that Recreation is important for: Social Interaction, Inclusion (#54 gives insight into this and many other reasons); Fun and interactions leads to more happiness; #43 Social activities are important for me to feel like a part of society; More services needed after age 22; helps to diminish feeling of loneliness; important for relationship building; emotionally important; #258 Nobody funds social and recreational activities on the level that our adults need it; Develop and sustain friends; The ID/DD community do not have the same opportunities for social interaction as others;**
- C. People want to be around others, not home alone and not always with other people with disabilities. Restore funding for Recreation . . . please! People need to exercise, mingle and have fun outside of the home.
- D. The main topic I heard over and over is people need socialization and need to be around ALL people in the community. There are so many reasons this is not happening. . Probably the biggest barrier is transportation.
- E. People would like “more information about places, programs, events, etc.”
- F. The connection of mind and body should not be separated; physical exercise and activities (Zumba, golf, bowling, attending major/minor league sporting events, movie theaters with accommodations – subtitles, lowered volume, no bass or sub-wolfers)
- G. Face-to-face interactions are important; building relationships
- H. Parents want their children’s social skills to increase (from contact and interactions with other people)
- I. More “special needs” parks – the play equipment and the public bathrooms
- J. Specialized activities like equine therapy; using sensory materials, such as, mud, paints, etc.
- K. Want to make friends so are not lonely
- L. Want something to do (bored)

2. *What about this topic is most important to you, as a Council member?*

- A.** Education and Outreach Workshops to provide more information on what is available and how to access it.
- B.** Help to create more recreational and social activities for the DD/ID community.
- C.** Foster more awareness about programs like Special Olympics.
- D.** Advocate for more funding for Social activities which are critically important.
- E.** Outreach to Rec Centers and Parks, Community programs, Religious Organizations to offer more programs for the ID/DD community.
- F.** #179 raises important Q about role of SCDD and our finding out about available programs and letting people know about them.
- G.** I would like to see more social activities that are age and developmentally appropriate. I would like to see more diversity in the social activities.
- H.** I need more options for socialization. There is nothing for the LBGTQ community also.
- I.** I want to meet people, however where?
- J.** Being social and staying active is important (physically and emotionally)
- K.** I see a need for engagement with animals and nature to build different types of skills (e.g., trusting, using caution, focusing on some of our difference senses)
- L.** Children with severe special needs are often simply left out
- M.** Awareness of loneliness and depression (more so for the adults)
- N.** #184 – “a well-balanced social life increases happiness”
- O.** Making sure people with I/DD are included in community activities that are affordable and adaptable

3. **Please check any related boxes if you believe that 1 or more other topics should be included (in combination) with Recreation & Social as a (combined) goal area:**

Health & Well-being (2)

Housing

Education

Employment

Formal/Informal Community Supports (4)

Quality Assurance

Early Intervention

Transportation (3)

Recreation/Social (4)

Child Care

Self-Advocacy (Required)

Other _____

4. **Explain why you do (or do not) want to combine this topic with 1 or more other topic areas:**

- A. Very important but can be considered with other categories. I wonder if Health and Well-being could be expanded by putting in parenthesis (Physical, Emotional and Social). That would lead to a natural integration of this area.
- B. Do not combine because this needs to be addressed as a big problem.
- C. It can be under Health and Well-being because recreation and social interaction is part of health and well-being.
- D. Mental and physical health go hand-in-hand – Health & Well-Being.
- E. Accessible and affordable activities (comment #144) require some mode of Transportation.
- F. Formal & Informal Community Supports are a literally natural part of Recreation.
- G. Need to teach our community social skills and inclusion
- H. Need to make sure folks have access to community activities and locales
- I. Want to improve quality of life

5. **How important is this goal area? (Please circle OR highlight your choice)**

1

2

3

4

5

VERY (3)

SOMEWHAT

NOT REALLY

Child Care

1. ***What about this topic was most important to survey respondents?***
 - A. For both groups, SA and FA near the bottom.
 - B. This is important so that parents, caregivers can have jobs, pursue higher education, attend workshops, meetings and seminars (where they can learn and gain skills for how to better raise their children and know what is available) and have some time to relax and recharge.**
 - C. Many children with special needs are not included in child – care programs.
 - D. #308 It is very important for parents to have a safe, affordable place to leave their children.
 - E. Many comments expressed concerns about the lack of quality child care options.
 - F. Lack of Child Care and I/DD children over the age of 12 who cannot be left home alone.
 - G. Access to childcare information
 - H. More funding needed
 - I. Having child care (or not) can impact the parent’s or caregiver’s quality of life
 - J. Finding safe, affordable, and reliable care is challenging and creates a strain when there is no break
 - K. Childcare is expensive and not specialized
 - L. Need better training

2. *What about this topic is most important to you, as a Council member?*

- A.** To make sure that we are mindful of this when offering workshops and other programs.
- B.** Provide more information about day care programs that include children with DD/ID.
- C.** Creating more awareness about the importance of childcare for parents and their ability to work or learn.
- D.** Offer training and more information for Child Care providers that help them better understand the needs of the DD/ID community
- E.** Respite is more important to me. I would like someone other than a family member who is nice and enjoys spending time with me. Some one I can connect with. But I think they deserve to be paid more.
- F.** HELP! Folks are (silently) screaming for help.
- G.** I found it frustrating, to say the least, to find age 0-3 providers who could accept "high risk" babies/toddlers. They were trained/certified, but terrified to provide care; and this was in a pretty well-resourced community in an urban setting.
- H.** School districts not having child care options for students in Special Day Classes
- I.** With Child Care, there are direct benefits to the caregiver, and indirect benefits for the client
- J.** Making sure childcare services are appropriate for the needs of children with disabilities so families do not have to go to untrained providers because of cost
- K.** Care for dependent adults

3. **Please check any related boxes if you believe that 1 or more other topics should be included (in combination) with Child Care as a (combined) goal area:**

Health & Well-being (2)

Housing

Education

Employment

Formal/Informal Community Supports

Quality Assurance

Early Intervention

Transportation

Recreation/Social

Child Care (4)

Self-Advocacy (Required)

Other _____

4. **Explain why you do (or do not) want to combine this topic with 1 or more other topic areas:**

- A. This area can be combined with Employment, Health and Education. For many people unless they have quality childcare they are unable to support their families, go to their own medical appointments or attend workshops as well as pursue their educational activities. It does not need to be its own goal.
- B. I do not see how this can be combined because it is a separate issue. However, Quality Assurance is something that every category needs.
- C. I see the resource of having Child Care as being directly correlated with Health & Well-Being. Caregivers are emotionally able to function better when there is an outlet or an opportunity to step away for a minute or two (Recreation & Social). Child Care could potentially allow parents to work, if they needed to.
- D. Childcare should include basic interventions, PBS, and intellectual stimulation to provide basic building blocks to transition to school
- E. Providers should be trained and overseen

5. **How important is this goal area? (Please circle OR highlight your choice)**

1 ————— 2 ————— 3 ————— 4 ————— 5

VERY

SOMEWHAT (2)

NOT REALLY

- A. **Note: It is very important for many when taken into consideration with health, employment and education.**

Other

1. *What about this option was most important to survey respondents?*

A.

2. *What about this option is most important to you, as a Council member?*

A.

3. **Please check any related boxes if you believe that 1 or more other topics should be included (in combination) with this Other option as a (combined) goal area:**

Health & Well-being

Early Intervention

Housing

Transportation

Education

Recreation/Social

Employment

Child Care

Formal/Informal Community Supports

Self-Advocacy (*Required*)

Quality Assurance

Other _____

4. **Explain why you do (or do not) want to combine this option with 1 or more other topic areas:**

A.

5. **How important is this goal area? (Please circle OR highlight your choice)**

1 _____ **2** _____ **3** _____ **4** _____ **5**

VERY

SOMEWHAT

NOT REALLY



Total Findings

Now that you have reviewed and analyzed the survey responses, please rank topic areas in order of importance (1-12):

- A. After a lot of thought, I realize that I cannot rank these. For me, I put Health, Education, Employment and Housing as all a number one priority. Depending on the year, one or two of these might get a higher priority. Also, it might depend on the stage of life. Health and Well-Being are life-long, but for a child, Employment is not relevant. However, in general they are all critical for people in the ID/DD community. Also, these and all the other goals are inextricably linked to the goal of becoming Self Advocates.**
- B. I consider transportation to be a supporting goal to all of these. Childcare is an essential support for employment, education and health. All goals need to have QA.**
- C. Early Intervention and Recreation/Social are essential for health and well-being.**
- D. Formal and Informal Community Supports is a very important category. I think a better shaped name might better describe this and also integrate Recreation/Social into it. Perhaps this goal is really captured in the other goals.**
- E. Possible rephrasing of goals, with brief descriptions.**
- F. Health and Well-being (Physical, Emotional, Social)**
- G. Education (Formal and Informal)**
- H. Livelihood (Employment and Volunteering)**
- I.**
- J.**



Total Findings

Now that you have reviewed and analyzed the survey responses, please rank topic areas in order of importance (1-12):

<u>10</u>	Child Care
<u>11</u>	Early Intervention
<u>1</u>	Education
<u>9</u>	Employment
<u>8</u>	Formal/Informal Community Supports
<u>4</u>	Health & Well-being
<u>7</u>	Housing
<u>0</u>	Other
<u>5</u>	Quality Assurance
<u>3</u>	Recreation/Social
<u>6</u>	Self-Advocacy (Required)
<u>2</u>	Transportation