



State Council on Developmental Disabilities

State Plan Committee

2022 – 2026 State Plan Development

Goal Development Worksheets

(Part 1)

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:**

Health & Well-being

Housing (4)

Education

Employment

Formal/Informal Community

Supports (3)

Quality Assurance

Early Intervention

Transportation (3)

Recreation/Social

Child Care

Self-Advocacy (*Required*) (2)

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)**

1

2

3

4

5

VERY (2)

(2)

SOMEWHAT

NOT REALLY

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 preskills 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.)

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

Health & Well-being

Housing

Education (2)

Employment (4)

Formal/Informal Community

Supports (2)

Quality Assurance

Early Intervention

Transportation (2)

Recreation/Social

Child Care

Self-Advocacy (Required) (2)

Other _____

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

A. It should not be combined because it is a big topic to deal with.

B. Need to find ways to cross-train individuals so they can explore different positions and eventually be independent.

C. The community support is essential to employment. One cannot exist without the other. Transportation should be a major consideration with employment as well (access to the jobs).

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

1

2

3

4

5

VERY

SOMEWHAT (2)

NOT REALLY

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.

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

- | | |
|--|--|
| <input checked="" type="checkbox"/> Health & Well-being | <input checked="" type="checkbox"/> Early Intervention (2) |
| <input checked="" type="checkbox"/> Housing | <input checked="" type="checkbox"/> Transportation (2) |
| <input checked="" type="checkbox"/> Education | <input checked="" type="checkbox"/> Recreation/Social (3) |
| <input checked="" type="checkbox"/> Employment | <input checked="" type="checkbox"/> Child Care |
| <input checked="" type="checkbox"/> Formal/Informal Community Supports (4) | <input checked="" type="checkbox"/> Self-Advocacy (Required) (2) |
| <input type="checkbox"/> Quality Assurance | <input checked="" type="checkbox"/> Other: IHSS, Medicare/Medi-Cal, DOR, Social Security & CalABLE |

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

- A.** I do not think it needs to be combined; I think it should be a higher priority. We are always so busy working on other things, but this directly impacts everyone.
- B.** This is really connected to everything, especially health, education and transportation.
- C.** Many of these other services require knowing about other service programs to be successful
- D.** Rec and social activities fit seamlessly with "community supports". Early intervention gets lost in the shuffle and overwhelmed by other needs/issue because those needing this essential service make up a smaller percentage of the I/DD population. This area ranks high on my list because it either addresses or is directly linked to all other areas.

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

1	—	2	—	3	—	4	—	5
VERY (2)				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):

- _____ Child Care
- _____ Early Intervention
- _____ Education
- _____ Employment
- _____ Formal/Informal Community Supports
- _____ Health & Well-being
- _____ Housing
- _____ Other
- _____ Quality Assurance
- _____ Recreation/Social
- _____ Self-Advocacy (Required)
- _____ Transportation