

Self-Determination Program Withdrawal Survey September 2020

Purpose and Background:

In October 2018 the Department selected 2,500 participants for the phased in implementation of the program. In November 2019, approximately 500 participants opted out and a second selection of participants was conducted to replace those who decided not to continue. Additionally, since it was anticipated more openings would occur during the phased in implementation, the Department selected 10% more individuals than the current number of openings. As of August 2020, there are 3,321 people who have been selected for the SDP and 1,051 people who have decided not to continue.

The Department of Developmental Services, and its Advisory Workgroup, realized the value of surveying selected participants who decide not to continue with the program in understanding the challenges and barriers in moving the program forward and in meeting the needs of those selected. A withdrawal survey was developed with input from the advisory workgroup and various stakeholders.

Information gathered from these participant and family responses will help the department's efforts to evaluate and improve the SDP with our partners and other stakeholder groups.

Process:

Beginning in December 2019, surveys are sent to people who were selected and decided to not move forward with SDP. Surveys are mailed out in preferred languages. There are two ways people can of respond to the survey: 1) online via Survey Monkey; or 2) by mail using a stamped envelope addressed to the Department.

As of August 2020, the Department mailed 857 surveys in Arabic (1), Cantonese/Mandarin (9), English (629), Hmong (1), Korean (8), Lao (1), Somali (1), Spanish (201), Tagalog (1) and Vietnamese (5).

On an ongoing basis, the department will mail a survey to participants who voluntarily withdraws from the program.

Results:

The Department received 148 responses; Majority of the surveys received were in English and Spanish with 73% of the responses in English and 23% of the responses in Spanish.

Some respondents did not answer all questions and some respondents marked more than one choice within a question. The percentages below are in relation to the total number of people who responded to that question and how many times they responded

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to that question. For example, on question #3 there were 131 people who provided 257 answers because more than one response pertained to their situation.

Data from the surveys is below:

- 1. Who is filling out form? (148 people with 152 answers)**
 - Consumer – 10.81%
 - Parent/Guardian – 85.14%
 - Other – 6.76%

- 2. Did you attend a Self-Determination Program Informational Meeting? (148 people with 148 answers)**
 - Yes – 77.03%
 - No – 22.97%

- 3. What interested you in the Self-Determination Program? (131 people with 257 answers)**
 - Making decisions about services I need or want – 53.44%
 - Picking my own service providers – 33.59%
 - Having more choices – 49.62%
 - Wanting more control of my services – 36.64%
 - Other reasons – 22.90%

- 4. Did you attend a Self-Determination Program Orientation? (143 people with 145 answers)**
 - Yes – 58.74%
 - No – 30.77%
 - I did not know about an orientation session (or I was not invited to an orientation session) – 11.89%

- 5. How confident are you filling out forms by yourself? (131 people with 131 answers)**
 - Extremely – 31.30%
 - Quite a bit – 25.19%
 - Somewhat – 12.98%
 - A little bit – 9.16%
 - Not at all – 21.37%

- 6. Why did you leave the program? (134 people with 230 answers)**
 - The amount of money I can use is not enough for what I need – 11.94%
 - Too much work to be in the program – 29.10%
 - The services I want to use are not allowed in the program – 5.97%
 - Too hard to find service providers for the program – 11.19%
 - Too many appointments – 10.45%
 - The services I am getting are fine for now – 39.55%

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- I am still interested, but there are other things in my life that make it difficult right now – 14.93%

- Other reasons – 48.51%. See comments provided:
 - **Satisfied with current services**
 - I am satisfied with the services I have through the regional center.
 - I wanted to explore this program but it seems that it can be very overwhelming for myself right now. I would prefer to continue with the amazing support from my daughter's service coordinator.
 - We wouldn't be able to keep our current service coordinator, and having such a great working relationship with her has been a tremendous help. We don't want to lose that.
 - Current program is meeting his needs at this time.
 - My son's coordinator at Tri-Counties is doing an excellent job.
 - In my opinion, the Regional Center has helped me and the staff is trained to do so since I've had their support for several years now.

 - **Difficulty understanding information about the SDP or too much work involved**
 - Everything's hard to understand. I think it's because I haven't delved into it. Besides, I've heard it's very difficult.
 - There is a lot of work to do for the items to be prepared, so I don't have the energy to handle it.
 - I did not understand how the program works but I am interested in my son participating in this program.
 - It's very complicated to understand it and apply it.
 - There were too many questions not explained.
 - Not clear what exactly is covered & who would determine if allowable. Too confusing to figure out fiscal mgt – system. What I have now is straight forward.

 - **Issues surrounding the Individual Budget / FMS**
 - The program is not well run at this point in time - maybe because it's new to LA County. I was told an in depth evaluation for my son would need to happen before moving forward with SDP. This would have to be paid up front, with RC reimbursing me for said costs. I don't have \$1,500+ in my bank account to cover this upfront. I later learned a vendor (thru Orange County) could have helped me, evaluated my son, and billed RC for services. This was not mentioned at the orientation meeting. It feels like this is extra work for case workers, they aren't prepared and I don't feel like I would have been properly supported. I may reassess my viewpoint once the program is finally established and functioning smoothly.
 - I feel like I will be tied up plus budget is not as much

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- My budget will be based on the past 12 month usage which was very long, instead of on a previous period which would have been much higher and representative of what would be needed to get my services. SDP would result in a 40% cut in services.
- Service providers I use do not want to participate the program. FMS provider is only a few and service fee is expensive.
- Too many unanswered questions that staff @ orientation was not able to answer. Current budget + added cost of required financial oversight = cost prohibitive for me.
- We are concerned that the cost to hire services privately will (1) lessen the amount of services received [due to RC buying power] and (2) limit availability of services for new needs. Also the requirement to manage payroll and taxes is daunting.

- **Miscellaneous responses**

- Minor's sibling was not selected
- My parents are in their late 70's & 80's and think it's a burden on them to set up the program, find the providers and then administer the program & finances would be too great and I cannot do that myself either.
- Could not attend a meeting since all were during work hours and far away from my home.
- When I was given the program, my worker was going to help me but then he quit and left me with no worker for 6 months. I was then assigned another worker who says there's no budget for me yet.
- It is too hard to find a Korean speaking facilitator, FMS, or provider.
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7. Was it hard to understand the Self-Determination Program information? (128 people with 129 answers)

- Very difficult to understand – 23.44%
- A little difficult to understand – 47.66%
- Easy to understand – 23.44%
- Very easy to understand – 6.25%

8. Was information provided in the language you use? (140 people with 142 answers)

- Yes – 94.29%
- No – 3.57%
- I did not know that I could ask for the information in another language. – 3.57%

9. Are there other reasons you do not want to be a part of the program? (110 people responded to this question)

- We are happy with the services provided through the regional center

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- The paperwork sounds complicated and complex
- Because of the comments made by people who have been doing it, saying it's quite difficult.
- My son is currently receiving behavioral therapy at home, as well as physical and occupational therapy by CCS. I'm focused on helping my son and I believe the self-determination program requires a lot of my time. At present, I prefer the Regional Center helping me as it has been doing so far.
- Individual wants to be a part of SDP but in order to arrange these kind of services would mean overseeing a lot of people, which would add stress to the situation
- Yes, I want to participate but I need the budget and more help understanding the program.
- I'm very happy with the social worker in charge and the programs my daughter is in
- No flexibility in how funds are used.
- Easier to stay in program and let RC do the work
- Parents and Service Coordinator should control the funds instead of the FMS

10. Would you be interested in participating in the SDP in the future? (109 people with 109 answers)

- Once it is available to everyone – 42.20%
- If it was available to all of my family members who are regional center consumers at the same time – 10.09%
- Other reason – 47.71%

11. Would you like to share anything else regarding the SDP? (144 people responded to this question)

- It's good but, for now, my child is young and I'm not ready to manage it.
- I haven't ruled out the possibility of participating in the program in the future but, for the time being, I'm not interested.
- This program didn't convince me since it's quite hard to understand Regional Center customers. We need a lot of moral and financial support for new programs. Please support and make more improvements to the Regional Center.
- I think my son needs quite a lot of help in language and sensory therapy. By the looks of it, this can't be requested in self-determination.
- Yes, that there be more individual informative communication.
- Does not offer appropriate programs according to my daughter's disability and her own needs: physical therapy and speech therapy.
- I hope there will be more Korean speaking facilitators, FMSs, or providers.
- Still unsure about the benefits compared to what she's getting at this time.
- The program requires a great deal of legwork and organizational skills. The vendors currently helping my daughter are well vetted and have exceptional employees. I believe this program might be best suited for higher functioning individuals or for consumers just leaving the school settings.

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- I don't think it is a good program for parents who are not educated or understand about the services their family is getting.
- Stop making people with Disabilities sit in some long meeting.
- Have to figure out accounts before I would join. It sounded like a big job with few, if any, vendors.
- I was overwhelmed. Information was hard to come by and hard to figure out. Too much information to take in, need more one on one help.