

## SDM Forum 02/20/21: Resources from the Chat

General Information: **Please direct questions to [info@dvunited.org](mailto:info@dvunited.org)**

- This call is being recorded and will be posted 3 places:
  - Our Facebook page - <https://www.facebook.com/disabilityvoicesunited>
  - Our YouTube channel - [https://www.youtube.com/channel/UC\\_nxJDP8YRw0nhdmuEWYdwQ](https://www.youtube.com/channel/UC_nxJDP8YRw0nhdmuEWYdwQ)
  - Our website - <https://disabilityvoicesunited.org/>
  - The Facebook livestream will be archived and available to view shortly after we finish here. For YouTube and the coronavirus website, please allow 2 business days for the recording to be edited, processed, and posted.
- To learn more about our SDM Conference and register:  
<https://campaign-ui.constantcontact.com/campaign/campaigns/list>
- To learn more about sponsorships opportunities:  
<http://events.r20.constantcontact.com/register/event?oeidk=a07ehj9cjeq4886a218&llr=9jtsrt9ab>
- CDAN surveys:
  - English survey for supporters of people with disabilities:  
<http://survey.constantcontact.com/survey/a07ehbfymyckfcu88ib/start>
  - English survey for people with disabilities:  
<http://survey.constantcontact.com/survey/a07ehbg1o8ukfcwd90t/start>
  - English survey for professionals:  
<http://survey.constantcontact.com/survey/a07ehbieaymkfea3fkc/start>
  - Spanish CDAN survey for supporters:  
<http://survey.constantcontact.com/survey/a07ehk690yekkok112t/start>
  - Spanish CDAN survey for self-advocates:  
<http://survey.constantcontact.com/survey/a07ehkaffdlkkpwmct/start>
  - Spanish CDAN survey for professionals:  
<http://survey.constantcontact.com/survey/a07ehk6gd7kkkon0dmu/start>
- A link to “What’s Next? A Self-Advocate’s Guided Tour Through Transition for Parents and Other Supporters” is available here:  
<https://www.aclu.org/other/whats-next-self-advocates-guided-tour-through-transition-parents-and-other-supporters>
- There is an entire section on financial forms you can fill out, as well as forms that can help you support somebody in the healthcare system, in the K-12 school system, and at university in our Supported Decision-Making Handbook:  
[https://disabilityvoicesunited.org/wp-content/uploads/2020/11/SDM-Handbook\\_Oct2020\\_6.pdf](https://disabilityvoicesunited.org/wp-content/uploads/2020/11/SDM-Handbook_Oct2020_6.pdf)
  - Page 15, where it talks about SDM in finances.
  - Page 33 in Handbook: Durable healthcare power of attorney
  - Page 36 in the Handbook: Durable POA for finances
  - Page 40 in the handbook: HIPAA authorization (this lets a person share their medical information with another person)
- <https://www.caltash.org/annualconference>

Judge Frances Doherty's presentation:

<https://drive.google.com/file/d/1UrJ-AmlrGkC1NO3AwdE5n2SNbDi2tUyv/view?usp=sharing>

Dr. Amy Hanreddy: Amy.hanreddy@csun.edu

- Here are some resources and my slides: ACLU Supported Decision Making Resource Library
- <https://www.aclu.org/other/supported-decision-making-resource-library>
- Decision Making When You Cannot Speak:  
<https://www.assistiveware.com/learn-aac/decision-making-when-you-cannot-speak>
- Child Preference Indicators:  
<https://www.imdetermined.org/wp-content/uploads/2017/10/child-preference-indicators.pdf>
- Personal Preference Indicators:  
<https://ouhsc.edu/thecenter/Publications/Publication-Details/personal-preference-indicators>
- Slides:  
[https://docs.google.com/presentation/d/e/2PACX-1vQJVPbldabyYmGowqfS3kPDIH7GWrkzQHepQFIkmP7PzYgx7YUO99obKRxD8-wZ9B\\_3E94eQJ1UO-/pub?start=false&loop=false&delayms=3000](https://docs.google.com/presentation/d/e/2PACX-1vQJVPbldabyYmGowqfS3kPDIH7GWrkzQHepQFIkmP7PzYgx7YUO99obKRxD8-wZ9B_3E94eQJ1UO-/pub?start=false&loop=false&delayms=3000)

Dr. Clarissa Kripke: Clarissa.Kripke@ucsf.edu

- For Spanish language and Chinese language information on Supported Decision Making check out the Office of Developmental Primary Care Website <https://odpc.ucsf.edu>. The whole website is translated.
- Kids who use AAC need role models. [www.CommunicationFirst.org](http://www.CommunicationFirst.org)'s video Listen is a place to start.
- <https://www.ODPC.UCSF.edu>
- <https://www.aclu.org/other/whats-next-self-advocates-guided-tour-through-transition-parents-and-other-supporters>
- Without communication there is no self direction. If you don't have a robust communication system here is a toolkit for you:  
<https://odpc.ucsf.edu/communications-paper>
- Here is advice for organizing and keeping control of meetings with medical professionals: <https://odpc.ucsf.edu/clinical/patient-centered-care>
- Navigating sexuality:  
<https://odpc.ucsf.edu/advocacy/sexuality-sexual-health/our-sexuality-our-health-a-disabled-advocates-guide-to>
- A handout on etiquette for communicating with non-traditional communicators:  
<https://odpc.ucsf.edu/advocacy/advice-from-self-advocates/non-traditional-communicators>
- What I Wish my Doctor Knew about People who Accompany us to Medical Appointments:  
<https://odpc.ucsf.edu/advocacy/advice-from-self-advocates/the-people-who-accompany-us-to-our-medical-appointments>

- Even people who are not able to engage in all parts of making an informed decision can provide information about their values and priorities. For example, a person may be able to express that they hate needles or don't want to go to a skilled nursing facility even if they are not weighing that against the benefits. The information about their will and preferences should be considered--not just their "best interest."
- Protections can be set up to prevent financial abuse. People with disabilities may need to learn the hard way like the rest of us in order to agree to them--e.g. it might be a good life lesson to allow someone to steal your kid's lunch money or allowance or not pay back a small loan before they control larger amounts of money as an adult.) Sample protections: A CalAble account with an Authorized Representative. The AR can put small amounts of allowance money on a prepaid card or who can put the money for specific purchases on a prepaid cash card you can get through that program. Special Needs Trusts can set up a trustee and trust protector system. Representative Payees can be set up for SSI funds.
- You can have financial power of attorney agreements too to manage larger sums of money or complex transactions. Again, people who can't manage the transactions may know who they trust to represent them and transact for them.
- You can also freeze credit accounts and set up fraud protections or have joint accounts. You can open a financial account in a bank that will send alerts to advisors or supporters when transactions are made or when funds are low, etc. Many bills can be put on electronic automatic payment.
- Typically developing kids and adults sign contracts for cell service that includes fees they don't understand. Typically developing kids and kids with disabilities need financial educations...and they both learn from mistakes.
- Conservatorship might avoid some financial problems, but can cause others in ways that can't be predicted. Some stories: parent died and court assigned a professional conservator to a client who had an \$8M settlement in a law suit. Instead of setting up a special needs trust, the conservator just let the settlement get spent down for medical costs that should have been paid by MediCal. Another story, conservator collected fees for her service while leaving money in bank benefitting the bank, but not the client. Remember, a judge will get to decide who the conservator is and you won't be able to serve forever. SDM allows people to grow.
- What I say to people who say SDM may not be for everyone is let's show you how we make it work for someone with a kid like yours! What are you worried might happen and let's practical problem solve to relieve your concern. Also, the person you know today isn't the person they will be in 10 years or 20 years or 50 years.

Ann Bui's presentation:

<https://drive.google.com/file/d/13ctn2hiTaf7lxGKEs7auNW-AOQsPSSJX/view?usp=sharing>

Kiely Rosalina's video:

<https://drive.google.com/file/d/1o3rIAaH9gCj7AJXOo0cxxdHZazjkQIXM/view?usp=sharing>

Resources from audience:

- Also need more like Dr. Martinis in the defense space, too. The 200+ pages' worth seem to have miraculously disappeared from the 2JDC Website, but, in case it gets missed, from the initial presentation both Judge Doherty and Dr. Martinis gave statewide, it has to have been a half-dozen years ago now, I highly recommend reading up on Jenny Hatch for lessons learned. :)
- In Davis where my son went there was a full inclusion model. He graduated with a diploma after having all modified classes. A diploma was a big mistake as he could not access school services. FYI
- Disability Rights California has a publication available that reviews alternatives to conservatorships, including SDM, durable powers of attorneys, and specific alternatives for multiple areas:  
<https://www.disabilityrightsca.org/publications/limited-conservatorships-alternatives>
- You can write Supported Decision-Making into or onto IEP and IPP documents and attach Supported Decision-Making agreements to legal binding documents like a Power of Attorney, HIPAA forms, SSI Rep Payee forms, etc.
- I am a teacher. I have assigned my son as the beneficiary to continue receiving my pension retirement. He also receives SSI and has MediCal and Medicare. How does the pension impacts his SSI, MediCAL, and Medicare? Response: Talk to an estate lawyer now! Giving a person who requires needs based public benefits money will make them ineligible. You will need to set up a trust.
- If not conserving, it would be crucial to set up financial controls so that the person is not taken advantage of with finances. The effects can be huge, such as large credit card debt, freezing of accounts, ruined credit, etc. So good to ensure that you have protections in place for the particular situation. (There are more online threats now than there were 10 years ago, or even 5 years ago.)
- Regional Centers MAY make medical decisions, but not other type of decisions on behalf of clients and only if there isn't any family, SDM supporter, or POA or other authorized representative involved. When regional centers do make medical decisions, they typically work hard to engage the client and everyone in their life in a team meeting to make it.
- You can contact the Office of Clients' Rights Advocacy for regional centers. There is a Clients' Rights Advocate assigned to help clients of every regional center in the state.
  - Program Description:  
<https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra>
  - Staff List:  
<https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra/ocra-staff-links>