# The Pragmatics of Supported Decision Making for People with Disabilities

## An Overview for Self-Advocates, Family Members and Supporters

# We all need help sometimes…

Most of us get support when making decisions.

Supporters:

- Help explain the situation and the significance of our decisions.
- Assist in figuring out options and their pros and cons.
- Provide emotional support in the process.
- Aid us in communicating our decisions to others.

# What is Supported Decision Making for People with Disabilities?

A law called AB 1663 enables people with disabilities (PWD) to choose to use or formalize these kinds of decision-making supports for themselves in **supported decision-making or SDM**.

In SDM, the PWD maintains their decision-making power, chooses supporters to help with decision-making, and makes the final decision.

The supporters and the types of support needed **can be written down into a supported decision-making agreement (an SDMA)** ***but they do NOT have to be written down.***

# Principles of SDM

✓PRESUMES COMPETENCE: Adults with disabilities are presumed competent to make decisions regarding their day-to-day health, safety, welfare, social and financial affairs.

✓ENCOURGES PARTICIPATION: The law hold that all adults, with supports they choose, should be able to be informed about, and participate in, the management of their affairs.

✓ VOLUNTARY SUPPORT: Adults with disabilities may use a wide range of voluntary supports to help them understand, make, and communicate their own decisions.

See AB 1663, sections 3950-3952

# Principles of SDM

✓INDIVIDUALIZED SUPPORT: SDM is an **individualized arrangement** in which an adult with a disability chooses one or more people they trust as supporters to help them understand, make, communicate, implement, or act on, their own choices.

✓FLEXIBLE: Supported decision-making is one of several options available to adults with disabilities to understand, make, and communicate decisions and to express preferences, including, but not limited to, medical and financial powers of attorney, authorized representative forms, health care directives, the release of information forms, and representative payees.

See AB 1663, sections 3950-3952

# Sounds great, how do you get started?

PWD can start SDM instantly by indicating the people that they want to support them – NO WRITTEN AGREEMENT NEEDED.

AB 1663 (section: 3953) is very clear that adults can have supporters in any meeting or communication concerning, but not limited to:  Individual Education Plans, Individual Program Plan, a service planning meeting, medical care plan or hospital discharge, financial planning, communication or meeting with bank or other financial institution, an employment planning meeting, or a medical appointment.

# All communication is valid in SDM

An adult with a disability may indicate that they wish to have another adult or adults attend a meeting by oral statement, gesture, or any ***augmentative or alternative communication method used by the adult with a disability.***

# Or a PWD may prefer a written Supported Decision Making Agreement (SDMA)

Think about decisions that you want support with…

Think about when you want that help…

Think about how you want them to help…

# NO WRITTEN AGREEMENT IS REQUIRED!

**BUT IF A WRITTEN SUPPORTED DECISION AGREEMENT IT IS DESIRED, IT SHOULD:**

- Be in easy-to-understand language.
- Include the name of the PWD, and names/contact information for the supporters.
- List the areas in which the adult with a disability requests support from one or more supporters.
- Include acknowledgments by each supporter that they agree to:

    - Provide information as requested by the adult with a disability.
    - Support the adult with a disability in good faith and to the best of their abilities.
    - Respect that the final decision shall be made by the adult with a disability and not the supporter.
    - Not coerce or manipulate the adult with a disability into making any decision.

# A POPULAR TEMPLATE  FOR SDM:

Many people use the ACLU Form, which you can access with this QR code.

While **not mandatory**, documenting the SDM arrangement in writing can provide clarity and prevent disputes.

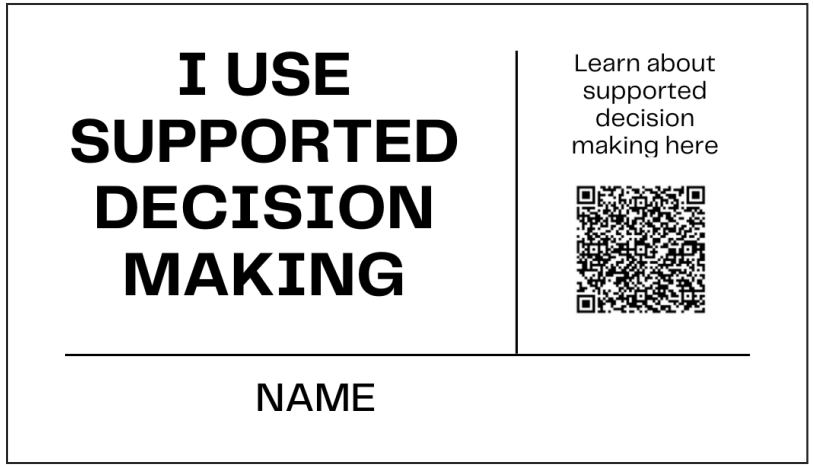
Written agreements can be notarized (this can be challenging depending on how the person communicates) OR

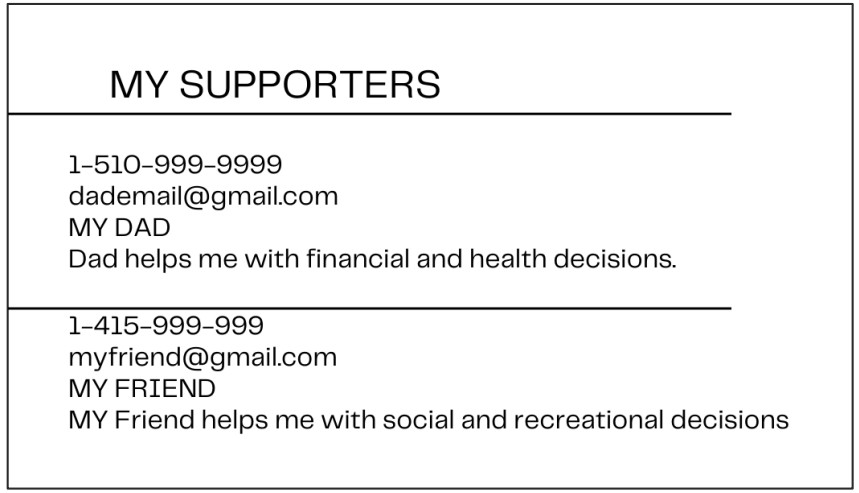
Witnessed by two people who verify that the PWD communicated this in their presence.

# Using Supported Decision Making

# How do I tell people I use SDM

- Practice a script or social story, “I use Supported Decision Making and I want help from…”
- Program a voice generating device (‘a talker’) to give your message of “I use SDM”
- Use cards like these to give to people.



# Using SDM for Education

Parents hold educational decision-making rights until a person is 18 years of age.

At that time, education rights revert to the adult, unless there has been legal action about this.

This should be discussed as  part of transition services under IDEA, which are intended to help transition the student to post school educational activities, work activities and living arrangements.

# PWD can use Supported Decision Making in the IEP Process

Manual on Supported Decision Making for Special Education (PEATC/Virginia)

# IEPs and Preparing for SDM

Decision making, advocacy and agency do not suddenly appear at 18.

For some people, these are skills that should be covered in IEPs through a student's career in an age and skill-appropriate way to develop these capacities.

# Examples: Advocacy and Decision-making Goals In the IEP

The District of Columbia Public Schools (DCPS) teaches students as young as three to use Supported Decision-Making and “build networks of support . . . to ensure that they are familiar with the process and utilize it in day-to-day activities.”

The student can develop this skill through practice (at home and at school) of age/developmentally appropriate choices.

For example, students can be encouraged the to identify any person(s) that they want to help them with decisions throughout their school career – whether that be elementary school playground activities or high school electives.

# Examples: Advocacy and Decision-making Goals In the IEP

Targeted self-advocacy IEP goals to address communication can help students voice their needs confidently; eventually, they engage more fully in their education and build a foundation for lifelong self-advocacy.

Self-advocacy IEP goals can help students gain the confidence to discuss their unique needs with teachers and ensure they receive the necessary support in the classroom.

Participating in their IEP meetings enables students with special needs to voice their opinions, share their strengths and challenges, and actively set their educational goals.

https://www.ablespace.io/blog/examples-of-self-advocacy-iep-goals-for-special-needs-students/

# School Staff May Be Unaware of SDM and Recommend Conservatorship

## Educate school staff!

Cal State East Bay, Center for Disability Justice Research , and DREDF are building online training on SDM and how to encourage its use by students (See https://www.csueastbay.edu/cdjr/supported-decision-making-outreach-team.html)

Consider alternatives to conservatorship!  Like SDM or the Assignment of Decision Making Authority forEducation for California (click on the QR code for the form from Disability Rights California) to a parent or a supporter.

# Using SDM for Healthcare

Supported Decision-making is used in healthcare settings all the time as most of us need help making these decisions.

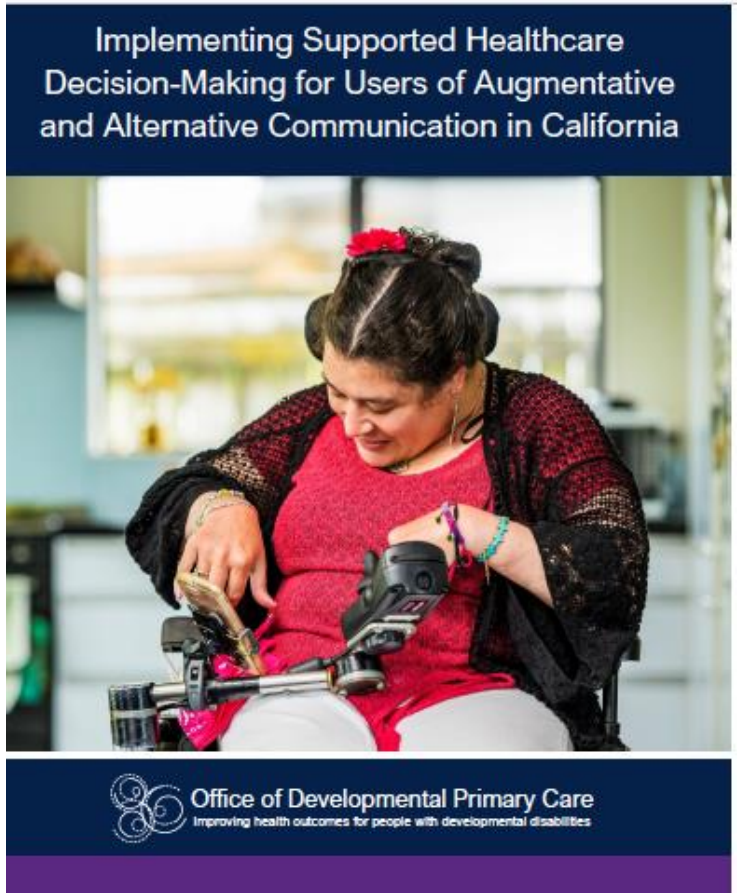
Healthcare is complex, and decisions (and release of information) may be needed for providers, insurance companies and hospitals.  There can be a high level of concern for liability by providers that makes these settings challenging to navigate.

PWD and their supporters may be most concerned about emergency situations where SDM is not easily accessible because of illness.

# Supporters can help:

- communicate with clinicians
- help with remembering to take medication or follow up
- translate complex medical concepts into plain language
- weigh treatment options
- make and prepare for medical appointments
- arrange transport to appointments
- take notes during appointments
- provide clinicians with a medical history and other information
- obtain medical and insurance information
- assist with physical tasks such as dressing or transferring onto exam tables
- pick up prescriptions or medical supplies

# Manual on Supported Decision Making for PWD (with a Focus on AAC Users) but great for any PWD.



# Companion Documents

- Authorized Representative: An authorized representative may act for you on all or some duties related to your medical eligibility and enrollment. This is often a form specific to a hospital, clinician, or insurer.
- Advanced Care Directive: An Advance Directive provides a way for people to direct their own healthcare even when they are in a coma, have dementia or are mentally incapacitated or unable to communicate. A person can use an Advance Directive to spell out their wishes regarding physical and mental healthcare and to select someone to make healthcare decisions when they are unable to do so. (See QR code for fillable CA form and https://www.disabilityrightsca.org/publications/advance-health-care-directives)

These may require notarization or the signature of two witnesses

# Using SDM with Regional Center

SDM can be used by PWD with Regional Centers

The new Individual Program Plan template explicitly documents when the PWN wants support with and from whom (including legally appointed decision makers).

The IPP should also document methods and preferences of communication used by the individual, what others need to know to communicate with the individual, supports or devices needed for communication and other information to share about how the individual communicates/understands.

**DECISION-MAKING**

**When making decisions about** click or tap here to choose a life area, **the support I want from others is:**
Click or tap here to enter text.

**The people who assist me with decisions are:**
Click or tap here to enter text.

**LIFE AREA** Click or tap here to choose a life area

**The outcome I desire is:**
Click or tap here to enter text.

**What is currently happening?**
Click or tap here to enter text.

**What is important to me?**

- Choose an item
- Choice/Advocacy
- Community Participation
- Education/Learning
- Employment
- Healthcare/Wellness
- Home Life/Housing
- Income/Finances
- Personal/Emotional Growth
- Relationships
- Safety Considerations
- Supports at Home
- Transportation/Getting Around

# New Individual Program Plan Template

# What if an adult needs help developing decision-making skills in a circle of support?

- If this is a goal for the adult, to develop decision-making skills or a circle of supporters, then this can be a goal for an IPP.
- Regional centers all offer, Independent Living Skills services (ILS) and ILS can be requested to help meet this goal.

“Independent Living Skills (ILS) services provide training and assistance for adults with intellectual/developmental disabilities to achieve greater independence while living with others or to acquire and maintain living independently.” (DDS website)

# Using SDM for Financial Matters

PWD can use supported decision-making to make decisions about money and finances.

More than most other areas of decision-making, there is a potential for conflicts of interest when using SDM for financial decision-making.

Supporters should take proactive steps to prevent real, perceived, or potential conflicts of interest.

The best practice is to plan ahead to address these conflicts before they happen. Many SDM templates ***include a separate role for financial monitoring***.

https://supporteddecisions.org/getting-started-with-supported-decision-making/sdm-and-financial-decisions/

# Companion Agreements/Arrangements

- Representative Payee: SSI/SSDI payments go directly to the representative payee. The representative payee is then responsible for paying the individual's bills, saving money, etc. , and must provide information to the Social Security Administration about how the individual's money has been spent.
- Power of Attorney: Giving someone  power of attorney means they have the ability to make financial and other business decisions on your behalf. Some PWD will use this as an addition to their SDM agreement.

# Companion Agreements/Arrangements

- Joint Bank Accounts: Some parents set up joint accounts with their children. As joint account holders, both make financial decisions and monitor how funds are used.
- CalABLE/Authorized Representative: CalABLE accounts allow individuals living with disabilities to save and invest money without losing eligibility for certain public benefits programs, like Medicaid or Supplemental Security Income (SSI). An authorized representative is someone who is allowed under state and federal law to make decisions for the CalABLE account beneficiary.

# Companion Agreements/Arrangements

- Special Needs Trusts: Special Needs Trust (SNT) allows for a person with a disability to maintain his or her eligibility for public assistance benefits despite having assets that would otherwise make the person ineligible for those benefits. A trustee holds, administers, and distributes all property allocated to the trust for the benefit of the disabled person during his or her lifetime.

# Where will you use SDM????  YOU DECIDE!!!

# QUESTIONS ?

California State Council on Developmental Disabilities

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