

Supported Decision-Making Teams: Setting the Wheels in Motion



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Introduction:

For thousands of years – going back to Ancient Rome – society treated people with intellectual disabilities as if they were unable to take care of or make decisions for themselves. Today, it is still expected that someone else – usually called a *guardian*, but in California, a *conservator* - will be appointed to make decisions for them. In fact, that is often the advice parents get when their children with disabilities turn 18: become their guardian/conservator as soon as possible. It doesn't *have* to be that way. This paper is about your options and actions you can take to help your children make their own decisions and direct their own lives to the maximum of their abilities.

I share this from my own experience. I am the proud mother of three children with disabilities. We have navigated our way through many systems, advocating for the tools, methods and resources they need to lead their best lives. I am the sister to a person with physical and mental illness. I watched with sadness when she was placed in a group home against her will, then shared her joy after she successfully fought to be released to her own supported apartment. I carry their experiences, their strength, and their values with me as contributing author and an educational advocate, where I help children and young adults receive the support and services they need to transition to adulthood.

In this paper, I will present ways to help your children *Set the Wheels in Motion* toward lives of independence. The journey starts with a question.

WHY NOT Guardianship/Conservatorship?

The difficulty with guardianship/conservatorship is that it takes away the person's Right to Make Choices, the basic right we all have to direct our lives to the maximum of our abilities. When people lose the right to control their lives, it's like they don't exist – someone else has the power to make



decisions like where they live, what they do, who they see, and whether they work.¹

In the last forty years, study after study has found that when people with disabilities have more control over their lives, when they make decisions for themselves – when they have more *self-determination* – they have better lives. People with disabilities who have more self-determination are more likely to be employed, independent, healthier, and safer.²

Because of this, we should empower people to *exercise* their Right to Make Choices rather than to *take it away*. There are many *less restrictive alternatives* to guardianship/conservatorship that can do that. One of the most popular is Supported Decision-Making or SDM.³

WHAT is Supported Decision-Making?

SDM can be defined as follows:

a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they make their own decisions⁴

If you think about it, that's just a fancy way to describe the way we all make decisions. We all get help from friends or family members when we need to make decisions. We may ask our brother, the

accountant, for financial advice or our sister, the doctor, to help us understand medical jargon.

So, if we can do it, shouldn't we give people with disabilities a chance to do it, too?



HOW CAN I KNOW that a Person can use Supported Decision-Making?

There are assessments that can examine a person's ability to make decisions and manage key areas of life with and without supports. For example, the Missouri Stoplight Tool⁵ examines a person's everyday abilities like managing money, working, and taking care of him or herself. However, no instrument is definitive or intended to provide a final determination of a person's abilities.⁶

Therefore, the best answer to the question "How can I know if a person can use SDM?" is this: You never know until you try. We should presume that everyone – including people with intellectual disabilities - has the right to make choices and everyone needs support until proven otherwise.⁷ So why not give the person the chance to use

¹ House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper)

² Wehmeyer & Schwartz, 1997

³ "The Right to Make Choices" is a phrase and concept developed by Quality Trust for Individuals with Disabilities (www.DCQualityTrust.Org) and The National Resource Center for Supported Decision-Making (www.SupportedDecisionMaking.Org). Quality Trust and the National Resource Center are national leaders in advancing everyone's Right to Make Choices through SDM. For more information, please see their websites.

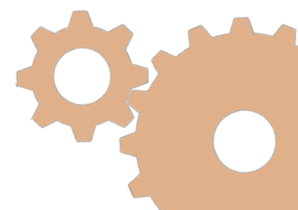
⁴ Blanck & Martinis, 2015

⁵ Missouri Stoplight Tool:

<http://www.moddcouncil.org/uploaded/Guardianship%20Manual%20Appendix%201.pdf>

⁶ Representing Clients in Guardianship Actions: Winning the Case for Supported Decision-Making, Jonathan Martinis, Esq., and Dr. C. Rick Ellis, Ed.D.: https://www.nclc.org/images/pdf/conferences_and_webinars/webinar_trainings/presentations/2014-2015/representing-clients-guardianship.pdf

⁷ Autonomy, Decision-Making Supports, and Guardianship, Joint Position Statement of AAIDD and The Arc <http://supporteddecisionmaking.org/news/autonomy-decision-making-supports-and-guardianship>



SDM: support him or her like you'd want to be supported or, even better, like he or she asks to be supported? That's the advice the National Guardianship Association – an organization made up of guardians and conservators – gives: try SDM before seeking guardianship/conservatorship.⁸



Setting the Wheels in Motion, Part 1: HOW can I help my Friend or Family Member use SDM?

When individuals, families and their supporters hear and think about using SDM, there is often a pause. Then the question: "What do we do *now*?"

As you think about that question, it is very important to stress the "WE." By its very nature, SDM is a process and a journey where no one can, should, or needs to "go it alone." The whole point of SDM is that it encourages people to seek out and work with others to help them. I use the term "Supported Decision-Making Team" to describe the individual and people who support him or her to make decisions. That's because SDM is truly a *Team Effort* with the person as the "captain" or "coach." When the team is working well together – *when the wheels are in motion* – the person is able to make his or her own decisions to the best of their abilities with the support of the team.

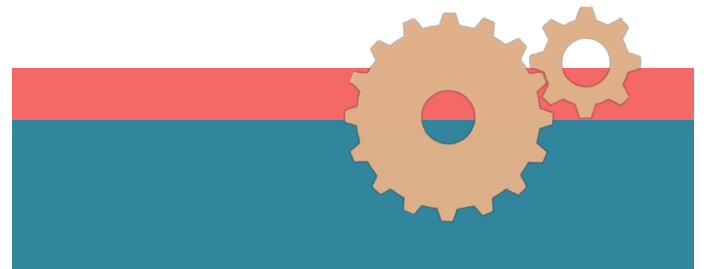
⁸ National Guardianship Association Position Paper: http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf

Because SDM will be a new concept to many people with exceptional abilities and their families, the entire process and the path can *seem* difficult or overwhelming. How can we discover what a person needs or wants help with? Or who the person wants help from?

The most important thing to do is to begin. *Set the wheels in motion!* A free-form brainstorming session can help the person think about and specify his or her wants, needs, and abilities.⁹ Because, after all, the individual with exceptional abilities should "drive" the process. So, don't over-think it. Listen to the person.

Setting the Wheels in Motion, Part 2: WHO should be on the SDM Team?

To find the answer to this question, ask the person. And ask yourself: Who shares the joys of this person and is driven by a like purpose? Who does the person connect with? Who is the person motivated by? AND, who can also meet the person's needs and wants? This may require people to stretch and reach for life's possibilities. You may need to look to people who are not currently participating in the individual's life. In our case, a long-time speech therapist, who we were unable to continue seeing, was the absolute clincher to connecting my daughter to the SDM journey. This "Gal Pal" of a therapist took my daughter shopping, into the community, and just "got" her. My daughter lit up with the mention of her favorite person who she had missed so much.



⁹ ACLU Brainstorming Guide: <http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

Here is a guide that may be able to help you as you think about who might be appropriate members of a SDM Team:

A good SDM Team member is:

1. Someone the person trusts and who is willing to go on the journey implementing SDM.
2. Someone who accepts and supports the individual/family.
3. Someone who has knowledge in a particular area we are seeking to include in the SDM agreement.
4. Someone that can be available long term (although changes to the Team should be anticipated over time).
5. Someone who is open to novel ideas, flexible and can make the individual "the agenda".

Setting the Wheels In Motion, Part 3: WHAT are the Goals of an SDM Team? HOW do we Know What to Work On?

Experience has taught us to think big picture at this stage rather than getting stuck "in the weeds." So think about the "big things" like:

- What are the person's goals?
- What does the person need to reach those goals?
- What's in the person's way from reaching his or her goals?
- Who can help and how?

You may want to consider asking those questions for several "life areas" like:

- Finances
- Medical
- Housing
- Employment
- Education
- Speech and Language
- Interpersonal/Social
- Behavior
- Self-Care/ADL (Activities of Daily Living)
- Organization
- Recreation and Leisure

In seeking SDM Team members, consider where these areas overlap. For instance, social skills may fall under the life areas of speech, behavior and community integration. Remember, we want to keep it simple - we don't need to know *all* the answers right now. It is important to start by having a conversation and setting goals. Think about what the person needs to reach those goals and who can help him or her do it. Generate a strategy that enables you to *Set the Wheels in Motion*.

Setting the Wheels in Motion, Part 4: HOW do we Schedule SDM Team meetings? HOW OFTEN should the Team Meet?

The schedule should be based upon the needs of the person, as well as the needs of any potential SDM Team members. What is manageable for everyone on the team and will help the person reach a successful outcome? In other words, what *works*? Our advice is, at least in the beginning: meeting frequently is better. That way, the team can get to know each other and learn the best way to work together. Over time, and through trial and error, you'll come up with a meeting schedule and style that works best for the person.



HOW can we Keep Team Members Engaged and Interested in this Process?

Once we have an idea of WHO the Team Members are and an initial schedule, *nurturing and fostering Team relationships is key*. In approaching potential team members, it is important not to overwhelm them - as a parent of three exceptional children, I have found this can often occur. Always remember and focus on the goal: helping the person make connections and develop decision-making skills.

As you begin working with the Team, you should make sure that all members are “up to speed” on the person’s current supports and services. That will help the Team understand what is available to help the person and identify “missing” supports to seek out. We have found the [SDM Parent Group - Individual Implementation Intake Form](#), which is attached in the **Appendix Table**, to be very helpful.

It can be hard work. People may get frustrated. But there is a sense of joy and relief when it “clicks!” I had an epiphany, a “light bulb moment” if you will, waking up at 4am with an idea about how to help my non-verbal, teenage daughter work with an SDM Team. I realized that she already had people in her life who she loved and trusted: an Educational Psychologist, Advocate and family friend; a Speech Therapist; some neighbors. By getting the team together, we could (and still are) able to focus on goals and resources that fit what *she* wants to do.

ALWAYS REMEMBER TO ASK: WHAT does our Unique, Exceptional Person Want?

It is tempting for family members and SDM Team members to play the lead role. But, remember, the person is the “captain” of the Team. So, if you have not already done so, STOP and ask the person what he or she wants and who the person wants help from. Remember: just because people need help *in* an area, it doesn’t mean they can’t make decisions *about* that area, or shouldn’t be given the chance to learn to do so.

Ask the person and yourself: What decisions does the person *already* make? How does he or she make them? Who does he or she connect with to help facilitate these decisions? That can give you a clue to his or her preferred way to make decisions. Another important question to ask is: What decisions are important to the person? What motivates him or her? Reinforcement surveys along with behavioral assessments and tools may be insightful for supporters and individuals who are non-verbal or who have intellectual disabilities. For my children, these interventions have been a key to understanding their thoughts and desires, so that we can support them to make decisions. The use of visuals along with daily, routine or ritualized practice of decision-making skills can be effective teaching tools. These abilities can be effectively captured and substantiated through data collection and video.

Once you know *what* is important to the person, and know *how* the person likes to make decisions, and *who* the person wants help from to make decisions, you can make a formal or informal SDM agreement that includes which decisions the person wants help with, who the person wants help from, and what type of help the person wants. This can be done through informal agreements or legal documents like a Power of Attorney.¹⁰

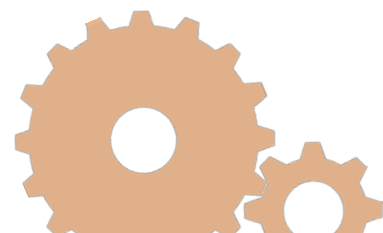
Setting the Wheels in Motion, Part 5: LET’S GET TO WORK

So much is possible even when the path is not clear. Now that you’ve set the wheels in motion, keep going! The ride may get bumpy. Keep going! There may be disagreements. Some Team members may not be a “good fit.” Difficult or “bad” choices may be made. Keep going!

Every Supported Decision-Making Team paves the way to a future where everyone has the Right to Make Choices, can direct their own lives, and truly has the rights to life, liberty and the pursuit of happiness.

Set the Wheels in Motion!

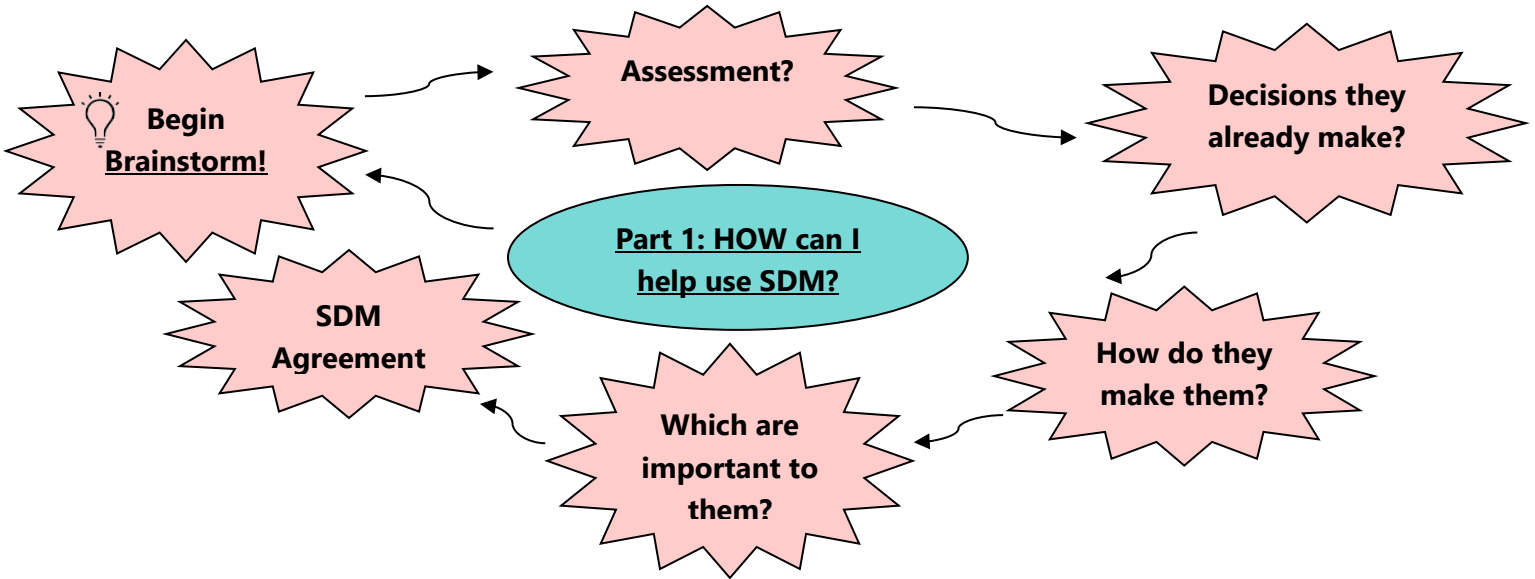
¹⁰ ACLU Sample SDM Agreements:
<http://supporteddecisionmaking.org/sites/default/files/sample-supported-decision-making-model-agreements.pdf>



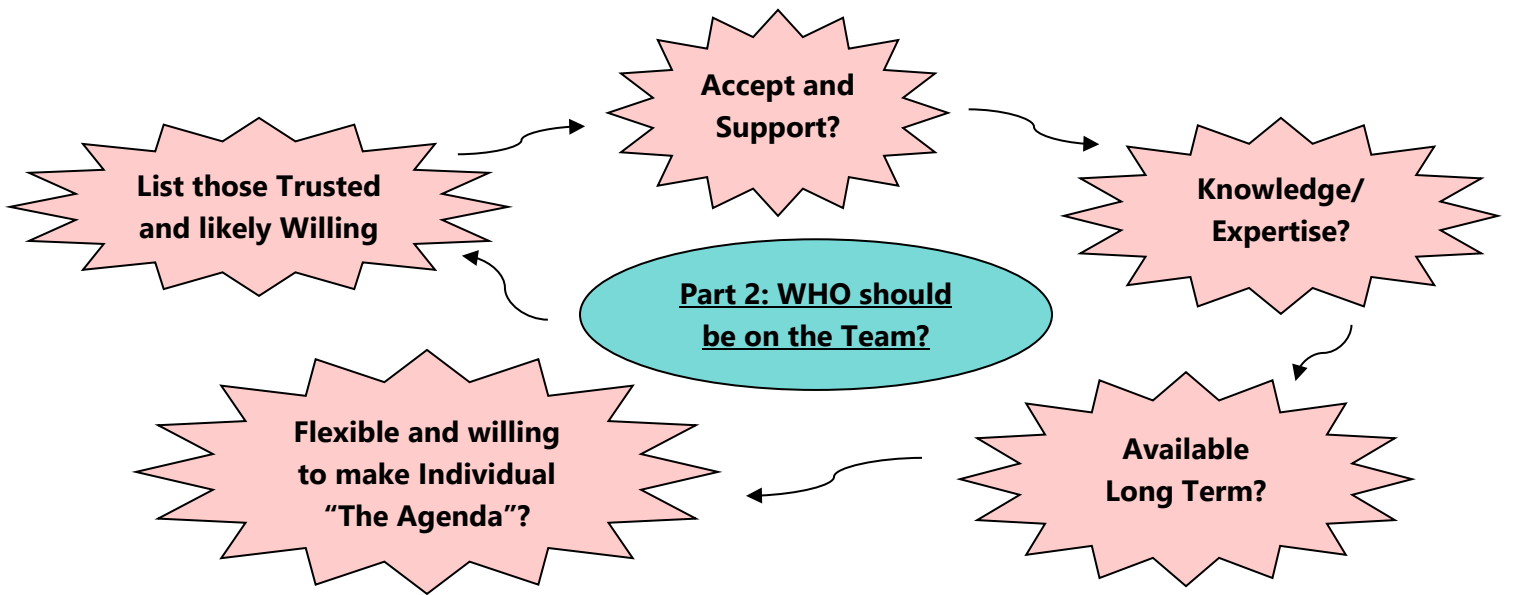
Supported Decision-Making Teams: Setting the Wheels in Motion

Date: _____ Individual with Exceptional Abilities: _____

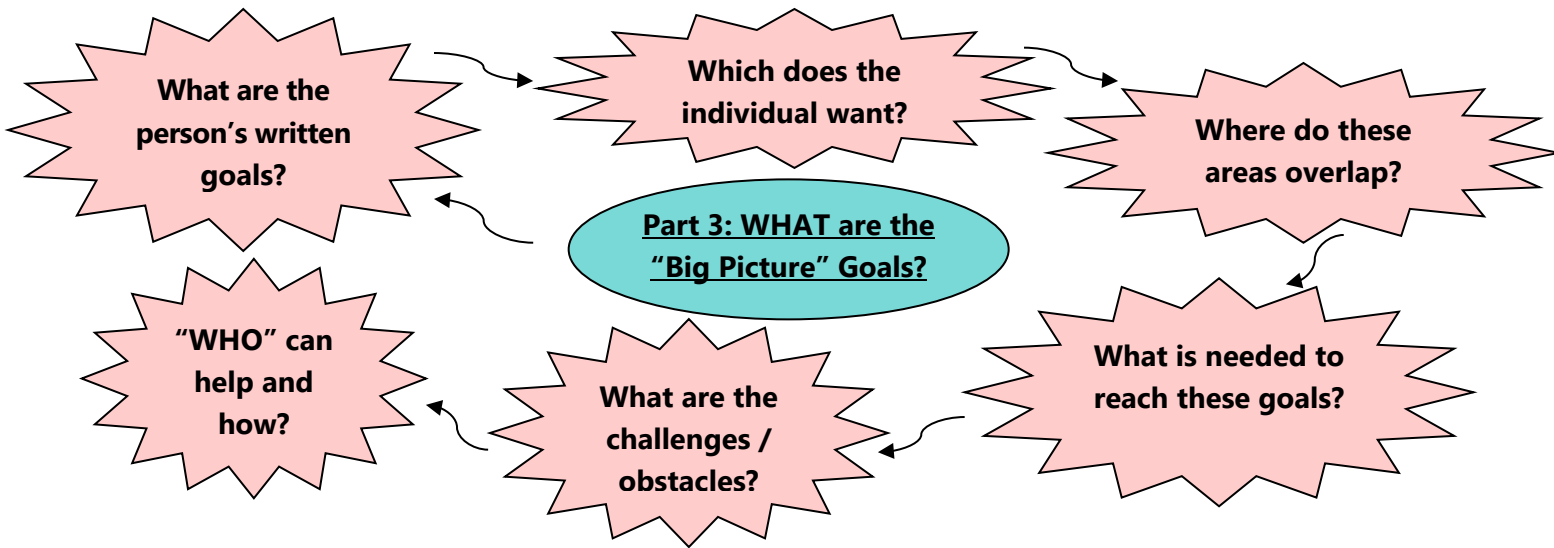
Current SDM Team Members or Assistants:



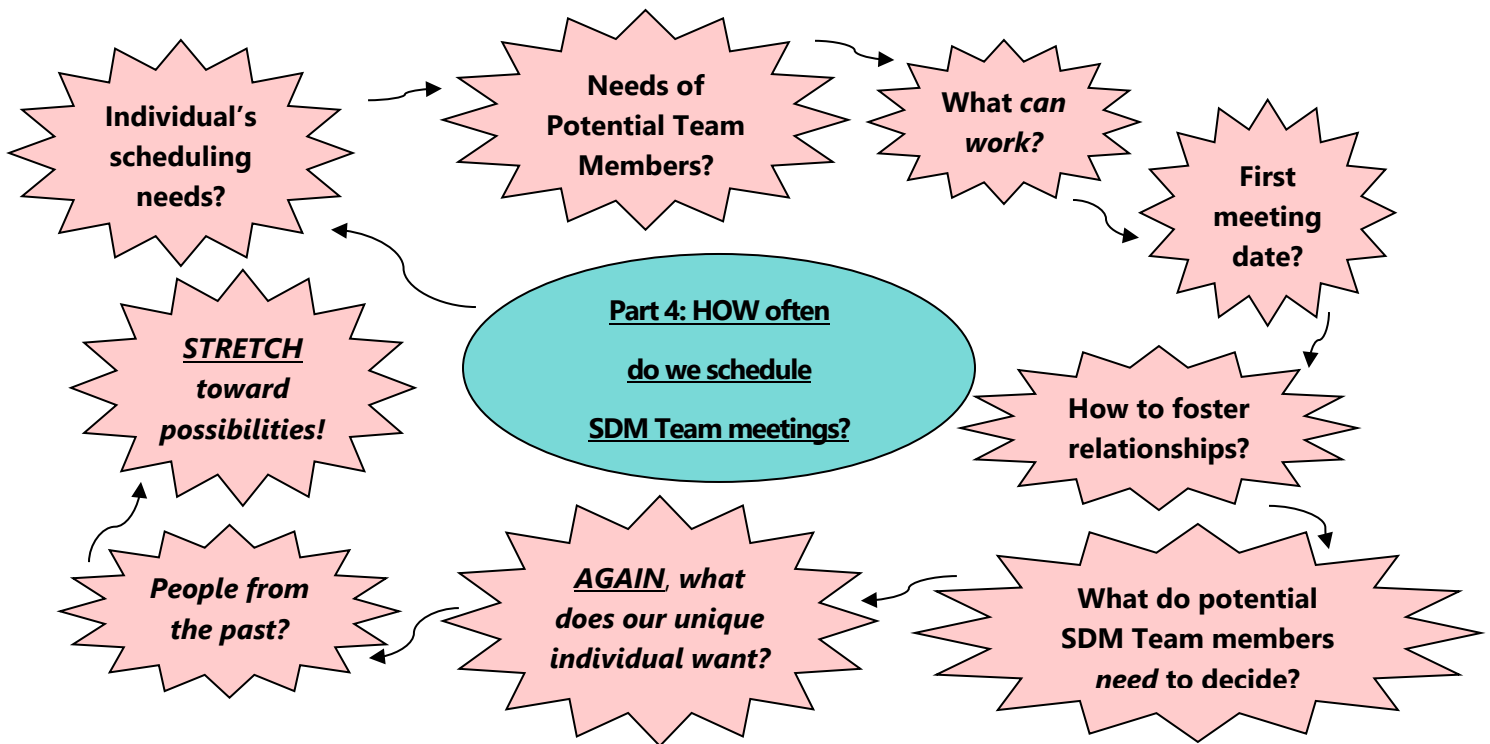
Part 1: HOW can I help my Friend or Family Member use SDM?
Start by BRAINSTORMING! (This can be free form or See ACLU Brainstorming Guide or others included in the SDM Toolkit attached.)
Is it necessary to have the individual assessed? Would it be beneficial? Are there assessments already completed that can help determine this person’s current decision making skills? (See suggested SDM Assessments in the SDM Toolkit attached.)
What decisions can and does the person already make?
How are these decisions made?
What decisions are important to the person? (See suggested sample SDM Agreements in the SDM Toolkit.)



Part 2: WHO should be on the SDM Team?
List people who are both trusted and likely willing to go on this SDM journey.
Do these people also accept and support the individual?
Do these people have knowledge/expertise in an area we may include in the SDM agreement?
Will they likely be available long term ? Could they be an interim Team member for the short term?
Are they flexible and willing to make the individual "the agenda" ?

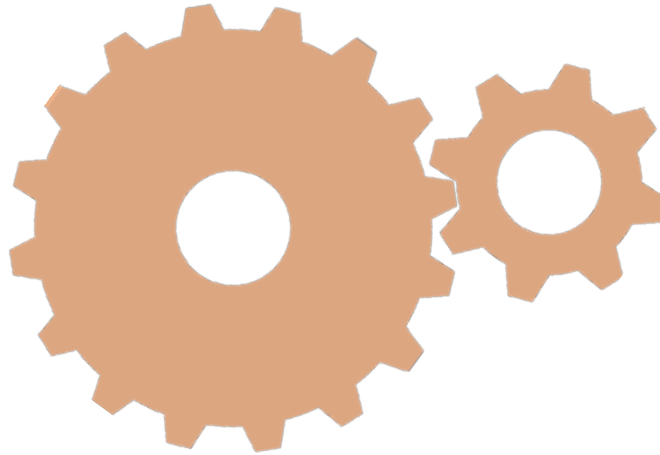


Part 3: WHAT are the Goals of the Individual and the SDM Team in the “big picture”?	
What are the person’s current or written goals? Reference the person’s current IEP (Individual Education Plan), IPP (Individual Program Plan), IPE (Individualized Plan for Employment), ISP (Individual Service Plan) and any other memorialized goals.	
Finance	Speech and Language
Medical	Interpersonal/Social
Housing	Behavior
Employment	Self-Care/ADL (Activities of Daily Living)
Education	Organization
What goals does the individual <i>personally</i> want that is <i>not yet memorialized</i>?	
Where do these areas overlap?	
What does the person need to reach those goals? Are PCP (Person Centered Planning) tools being used? Is the individual using resources like the SDP (Self-Determination Program)? (Links available in the SDM Toolkit.)	
What are the challenges/obstacles to success in achieving these goals?	
“WHO” can help and how? Do they have an expertise? What do they bring to the team? These should not only include potential SDM Team members, but also resources and people who may not be on the Team. (i.e. job coach, a case manager, a therapist or other professional, family or friends.)	



Part 4: HOW do we schedule SDM Team meetings? HOW OFTEN should the team meet?
What are individual's scheduling needs ?
What are the needs of potential SDM Team members ?
What is plainly manageable for everyone on the Team to begin? Can the Team meet monthly or biweekly? Will they meet in-person or by phone? What can work?
When is the first meeting date? © Remember we are Setting the Wheels in Motion!
How are we nurturing/fostering relationships with the SDM Team members?
Are we still in the discovery process? What information do the potential SDM Team members need in order to decide if this will work for them? Remember to keep it simple.
Go back and ASK AGAIN, what does our unique, exceptional person want? Remember decision-making skills build over time.
Who ...
<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;"> <p>shares joy with</p> <p>is driven by a common purpose of</p> <p>connects with</p> </div> <div style="width: 45%;"> <p>motivates</p> <p>can meet the needs and wants of</p> <p>would be thrilled to be on the Team for</p> <p>... the individual?</p> </div> </div>
Have we considered people involved with the individual from the past ?
Have we stretched to reach out for life's possibilities ?

WE can SIMPLY begin one step at a time! Time to SET the WHEELS in MOTION!¹



¹ This paper was supported, in part, by a grant from The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILIRR) within the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official NIDILIRR or ACL policy.

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Appendix Table: [SDM Parent Group - Individual Implementation Intake Form](#)

SDM Resources: A Toolkit for the Success of Exceptional Individuals

- **Supported Decision Making: Protecting Rights, Ensuring Choices:**
<https://youtu.be/Q8Na88Wz90I>

- **National Resource Center for Supported Decision-Making:**
<http://supporteddecisionmaking.org>

- **The Next Generation of Freedom and Self-Determination: Moving Supported Decision-Making from Theory to Practice Webinar Series:**
Youth in Transition (DC Schools)
Medicaid, Home and Community Based Services Settings Final Rule
ABLE Act, "Achieving Better Life Experience"
<http://supporteddecisionmaking.org/events/supported-decision-making-and-youth-transition>

- **Supported Healthcare Decision Making:**
 - **National Resource Center for Supported Decision-Making,**
www.supporteddecisionmaking.org

 - **UCSF Office of Developmental Primary Care,** <http://odpc.ucsf.edu/supported-health-care-decision-making>

 - **Special Hope Foundation,** <http://specialhope.org/resources/>

- **Videos of Individuals and Families implementing SDM:**
 - **Special Hope/ACLU Supported Decision Making: Gabby's Story**
<http://youtu.be/duyJkZ2mIQ>

 - **Delaware Supported Decision-Making: Your Support, My Decisions**
<http://youtu.be/dGJe5KyflxM>

 - **Massachusetts Nanotucket SDM Pilot – Woman with Down Syndrome**
<http://youtu.be/wfsMAM78IXk>

- **IDEA/U.S. Department of Education:** <http://idea.ed.gov/>
 - **Purpose of IDEA:** "... prepare them for further education employment, and independent living."
20 U.S.C. § 1400 (d)(1)(A)
<http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E1%2Ca%2C>

 - **IEP (Individualized Education Program):** 34 C.F.R. § 300.320

<http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CD%2C300%252E320%2C>

- **Transition Services:** "... post-school adult living objectives, and when appropriate, acquisition of daily living skills." 20 U.S.C. 1401 (34)
<http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E43%2C>
 - **What's Next?: A Self-Advocate's Guided Tour through Transition for Parents and Other Supporters**
UCSF LINK: http://odpc.ucsf.edu/odpc/html/for_self_advocates/index.html#
DIRECT LINK:
http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/FINAL%20Trans%20Guide%2011.18.16%20ALL_0.pdf
 - **Ten Tips That May Help Your Child's Transition To Adulthood**
<http://www.pacer.org/parent/php/PHP-c107.pdf>
 - **Center for Parent Information and Resources:**
<http://www.parentcenterhub.org/repository/transitionadult/>
 - **Charting The Life Course: Transition tools and webinars**
<http://mofamilytofamily.org/get-information/lifecourse/life-stages/transition/>
- **California Department of Education:** <http://www.cde.ca.gov/index.asp>
- **National Association of Councils on Developmental Disabilities (NACDD):** <http://nacdd.org/>
- **California: The Lanterman Developmental Disabilities Services Act and Regional Centers:**
http://www.dds.ca.gov/Statutes/Statutes_Home.cfm
<http://www.disabilityrightsca.org/pubs/506301Ch01.pdf>
- **IPP (Individual Program Plan)**
<http://www.dds.ca.gov/RC/RCipp.cfm>
<http://www.disabilityrightsca.org/pubs/506301Ch04.pdf>
- **PCP (Person Centered-Planning)**
 - **Person Centered Planning: A Tool for Transition**
<http://supporteddecisionmaking.org/legal-resource/person-centered-planning-tool-transition-0>
 - **Person Centered Thinking Tools:** <http://www.php.com/#!/pct-tools/tfkne>
 - **PCT for those with Chronic Health Issues: Think About Your Life, Easy Thinking Tools for Living Well by Think and Plan:** <http://www.thinkaboutyourlife.org/>

- **PCT One Page Profile Templates by Think and Plan:** <http://www.thinkandplan.com/one-page-profiles.html>
- **Tools for those with training in Person Centered Thinking by Think and Plan:** <http://www.thinkandplan.com/person-centred-thinking.html>
- **California: SDP (Self-Determination Program)**
<http://www.dds.ca.gov/SDP/Index.cfm>
- **Department of Vocational Rehabilitation**
<http://www.ecfr.gov/cgi-bin/text-idx?SID=61dfb3cfca74e84c319c2badb25c5c56&mc=true&node=pt34.2.361&rgn=div5>
<http://www.rehab.cahwnet.gov/Vocational-Rehabilitation.html>
 - **Coordination with education officials:** 34 CFR §361.22 http://www.ecfr.gov/cgi-bin/text-idx?SID=61dfb3cfca74e84c319c2badb25c5c56&mc=true&node=pt34.2.361&rgn=div5#se34.2.361_122
 - **IPE (Individual Plan for Employment):** 34 CFR §361.45, Development of the individualized plan for employment. <http://www.ecfr.gov/cgi-bin/text-idx?SID=61dfb3cfca74e84c319c2badb25c5c56&mc=true&node=pt34.2.361&rgn=div5#sp34.2.361.a>
- **Medicaid Waiver**
 - **ISP (Individual Support Plan):** https://secure.in.gov/fssa/files/ISP_Form.pdf
 - **HCBS (Home & Community Based Services):** <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>
 - **HCBS, Frequently Asked Questions:**
<http://www.dds.ca.gov/HCBS/docs/faqRules.pdf>
 - **Fact Sheet: Home and Community Based Settings Rule:**
<http://www.dds.ca.gov/HCBS/docs/hcbsFactSheet.pdf>
 - **HCBS Advocacy**
<https://hcbsadvocacy.org/learn-about-the-new-rules/>
 - **HCBS Waivers, California Department of Developmental Services**
<http://www.dhcs.ca.gov/services/Pages/HCBSWaiver.aspx>

- "...community participation, employment income and savings, healthcare and wellness education." www.medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf
- **California: Medicaid Waiver Institutional Deeming**
<http://www.sclarc.org/pdf/Medicaid%20Waiver%20Institutional%20Deeming.pdf>
- **Housing/Living Options**
 - **Living Arrangements for Persons with Developmental Disabilities, California Department of Developmental Services**
<http://www.dds.ca.gov/LivingArrang/Home.cfm>
 - **Living Options - Parents Helping Parents**
<http://www.php.com/#!ac-living-options/v64bv>
 - **ILS (Independent Living Services), California Department of Developmental Services**
<http://www.dds.ca.gov/LivingArrang/IndLiving.cfm>
 - **National Council on Independent Living**
<http://www.ncil.org/>
- **SLS (Supported Living Services)**
 - **Supported Living Services, California Department of Developmental Services**
<http://www.dds.ca.gov/sls/>
 - **California Supported Living Network**
<http://www.supportedliving.com/>