

Your Partner For A Stronger Arizona



Division of Developmental Disabilities September 7, 2023

Agenda

- Parents as Paid Caregivers (PPCG)
- Quick Reference Guides and Videos
- Supported Decision Making Melanie Soto, State Director at The Arc of Arizona, and Sey In, Attorney with the Arizona Center for Disability Law (ACDL)

AHCCCS extended this flexibility until November 11, 2023 with no changes

- Began at start of COVID-19 to ensure families had support during the emergency
- AHCCCS worked with CMS allowed parents to become Direct Care Workers (DCW) for their children receiving DDD benefits
- Allowed Qualified Vendors to hire parents to provide services for their minor children

AHCCCS plans to amend the 1115 waiver to

- Address shortage of Direct Care Workers/caregivers by allowing payments to parents who are paid caregivers for their minor children
- Increase satisfaction and promote positive health and well-being outcomes for children
- Extend a support service to preserve effective care for the member in the home and community
- Ensure members receive high-quality care while increasing timely accessibility to care providers

AHCCCS Opened and Closed Public Comment Period

- AHCCCS completed two (2) virtual public forums
- Public comments closed on August 21, 2023
- Posted <u>Data</u> about the PPCG program
- Posted <u>Final Draft</u> August 24, 2023
- AHCCCS had a Post Public Comment Forum September 6, 2023
- Will submit draft to Centers for Medicare & Medicaid Services (CMS)

Included in the Proposed Draft to be Submitted to CMS

- Support Coordinators will use a decision tree to help make an informed decision regarding the model that will best meet the member's needs, including decisions about using:
 - DCWs recruited by the agency and/or member/family,
 - Non-parental family members, and/or
 - Parents as a last resort when other options have been exhausted and when the parent is willing and able to provide the paid care.
- Habilitation was included: The PCSP shall include an individualized habilitation goal to address interaction with peers in community settings.

Included in the Proposed Draft to be Submitted to CMS

- Parents must participate in quarterly in-person case management and supervisory visits
- Parents will be limited to 40 hours of paid care, per child, in a given week where paid care by a parent caregiver.
- Care by a parent cannot exceed more than 16 hours in a single day (16 hours in a 24 hour period).
- If two children are receiving direct care services (habilitation & attendant care services), the parent(s) may provide up to a combined 80 hours of paid care per week (40 hours for each child).
- The exact number of authorized hours (up to 40 per child) will be determined through the person-centered planning process. Members can still receive more than 40 hours of authorized paid care in a given week through the use of an alternate caregiver.

Included in the Proposed Draft to be Submitted to CMS

Phased in Approach for families already enrolled in the program and currently providing care over the 40 hour limit:

- From the time of approval until January 31, 2024: There will be no hourly limitations in place.
- From February 1, 2024, until May 31, 2024: There will be an 80 hour per week limitation.
- From June 1, 2024, to September 30, 2024: The hourly limitation will drop to 60 hours a week.
- Beginning October 1, 2024, and thereafter: The 40 hour per week limitation will be in effect.

Included in the Proposed Draft to be submitted to CMS:

- Providers (Qualified Vendors) must ensure they have active and implementable workforce development plans that are reflective of their entire current membership, not just parents
- AHCCCS is developing a new services called family support

New Quick Reference Guides

- DDD launched a new online library of Quick Reference Guides short PDF documents on topics relevant to the people DDD supports
 - Parents as Paid Providers for Their Minor Children
 - Getting the Most from Your Pharmacy Benefits
 - AHCCCS Eligibility Redeterminations
- Effort to improve plain-language communication and education

New Quick Reference Guides (cont.)

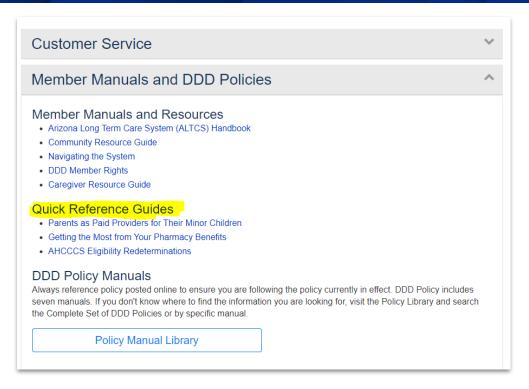
Find them on <u>DDD's</u>

webpage for Members and

Family Resources under

"Member Manuals and DDD

Policies"



If you joined late, click the INTERPRETATION button at the bottom of your Zoom screen and select English or Spanish to hear the meeting. Si se unió tarde, haga clic en el botón INTERPRETACIÓN en la parte inferior de la pantalla de Zoom y seleccione Inglés o Español para escuchar la reunión.

Online Educational Videos

- Over past four years, DDD also published educational and informational videos
 - Planning Meetings and Assessments
 - What to Do When You Have a Complaint
 - And more!
- Find the videos on the DDD website:
 - https://des.az.gov/services/disabilities/developmental-disabilities/DDD-informational-videos



Your Partner For A Stronger Arizona



Questions?

Arizona Supported Decision-Making



For People with Disabilities and their Supporters

Supported Decision-Making Project is Funded by Arizona Developmental Disabilities Planning Council







Presenters

Melanie Soto is the State Director for The Arc of Arizona. She has been with The Arc for 21 years and has spent her entire career supporting and advocating for the IDD community. She has served on various advisory committees and coalitions including those focused on guardianship & supported decision-making training and supports.

Sey In is a staff attorney with the Arizona Center for Disability Law (ACDL). He has been with ACDL for 5 years working on various issues involving healthcare and civil rights matters. He has trained various stakeholder groups on supported decision-making.

Purpose of our presentation



Supported Decision-Making



What is Guardianship?

Decision-making and autonomy

SDM

• Individual retains decision-making rights.

- Legally recognized options that enables an individual to appoint an agent.
- Examples: POA, HPOA, Delegation of Educational Rights, and Rep Payee.

• Tailored guardianship where an individual loses specifically petitioned rights.

- Conservator guardian of the estate; Guardianship guardian of the individual.
- Individual loses all decision-making rights.

What is guardianship?

Definitions and Requirements under State Law

Individual Rights

The Process

Guardianship vs. Conservatorship vs. Limited Guardianship

Recent State Law Changes

Legal Definitions and Obligations

- A <u>guardian</u> is someone who has the legal authority to care for another.
- A person subject to <u>guardianship</u> is someone who is <u>impaired</u> by reason of mental illness, mental deficiency, mental disorder, physical illness or disability... to the extent they do not have <u>sufficient understanding</u> to the extent that they lack <u>sufficient understanding</u> or <u>capacity</u> to make or communicate responsible decisions.
- A guardian is appointed to help the individual when the individual, because
 of their disability, is unable to communicate and care for themselves.

Individual rights

Voting

Healthcare Decisions

Education or Training

Consenting to Marriage

Financial Decisions

Guardianship Process

The Petition

• An interested party may petition the court for guardianship.

Notice and Hearing

- The individual must be given notice
- Right to counsel, present own evidence, have own medical tests conducted

Evidence

- Standard: clear and convincing
- Medical testimony, court investigator report, other testimony
- Judge or commissioner will make a ruling as to whether guardianship is needed

Powers and Duties of a Guardian A.R.S. § 14-5312

- Care, comfort and maintenance
- Training and education if appropriate
- Find the most appropriate and least restrictive setting
- Finding appropriate medical and psychological care
- Must take the individual's values and wishes into account

Limited Guardianship

- A limited guardianship can be requested with the following specific powers:
 - Consenting to medical treatment
 - Arrange education or training
 - Apply for public assistance or social services
 - Consenting to outpatient mental health care and treatment
 - Consent to make living arrangements
 - Consent to marriage
- Driving and <u>Voting</u> Privileges
 - A person for whom a limited guardian is appointed shall retain the right to vote if the person files a petition, has a hearing, and the judge determines by clear and convincing evidence that the person retains sufficient understanding to exercise the right to vote.

More about voting under limited guardianship

- What does the law say?
 - A person for whom a limited guardian is appointed shall retain the right to vote if the person files a petition, has a hearing, and the judge determines by clear and convincing evidence that the person retains sufficient understanding to exercise the right to vote.
- How do you file a petition?
 - Go to the courthouse, in your county, or visit them online, and ask for the form to fill out

Other Rights under limited guardianship

The petitioner, the prospective guardian, can ask the Court to grant guardianship in specific areas.

These areas include:

- Consent to medical treatment
- Arrange education or training
- Apply for public assistance or social services
- Consent to outpatient mental health care and treatment
- Consent to make living arrangements
- Consent to marriage

The court will determine if limited guardianship is appropriate for the petitioned areas.

Supported Decision-Making Becomes Law

• A.R.S. § 14-5722

Details the scope, rights and obligations of supported

decision-making agreements

Discusses the supporters' roles

Includes a template form

Supported Decision-Making



What is Supported Decision-Making?

Choices, choices, choices...



Sometimes we ask for help



Sometimes we ask for help

And that's -

Supported Decision-Making

Supported Decision-Making can also include...

- What to have for dinner
- Making decisions about health care
- What type of program to study
- Which job to do
- ...and much, much more

Making decisions can be a lot of responsibility!

If that's the case, Supported Decision-Making might be a good solution

- Helps people with disabilities keep their rights as adults
- Offers guidance and assistance from people they trust
- Creates a formal network of volunteer supports to help a person with a disability make decisions and life choices

Supporters

Volunteers who help person with disability make decisions

Could include:

- Family members and caregivers
- Personal and family friends
- Teachers and counselors
- Religious or faith leaders
- Coaches or recreation specialists
- Employment specialists and/or employers
- Financial and legal advisors
- Healthcare professionals (medical, dental, psychological/psychiatric)

All sign a legal Agreement to do what's best for person with a disability

So, what is Supported Decision-Making?

It's people with disabilities retaining their rights

It's volunteer supporters providing guidance and assistance

It's individuals with disabilities utilizing the support of people they trust to make their own decisions about the direction of their lives

Supported Decision-Making



Deciding if Supported Decision-Making is Right for You

Deciding if Supported Decision-Making is Right for You

Supported decision-making is all about receiving the right support at the right time to live as independently as possible.

Charting the LifeCourse Toolkit

lifecoursetools.com/lifecourse-library/lifecourse-framework/

Remember: SDM involves individuals with disabilities making choices



with the proper support

Supported Decision-Making requires capacity to:

- Communicate wants and needs
- Make decisions for self
- Learn from mistakes

Ask Yourself This:

Given the right support, can the person with the disability make decisions for himself or herself?

How can you decide if it's right for you?

- Can the individual with a disability express his/her choices?
- What types of support does person with disability need?
- How much support does person with disability need – and how often?

If the answer is "YES"...



Planning is ESSENTIAL

Topics You May Wish to Consider

- Finances
- Social Services
- Healthcare
- Housing
- Employment
- Education
- Transportation

Planning is Not a One-Person Job!

SDM Planning can involve these and others:

- The person with a disability
- Family members and caregivers
- Personal and family friends
- Teachers and counselors
- Religious or faith leaders
- Coaches or recreation specialists
- Employment specialists and/or employers
- Financial and legal advisors
- Healthcare professionals (medical, dental, psychological/psychiatric)

Needs differ...and so does every Plan

Here's an example:

Area of Support	How I Would like Support			
Finances	Assist with paying my bills on time Assist with managing my bank account			
Medical	 Attend doctor appointments with me to make sure I understand what the doctor says Assist with organizing my medication 			
Employment	 Assist with finding a job I will like Assist with filling out job applications Assist with making sure I know how to get to my job safely and on time 			

Needs differ...and so does every Plan

Area of Support How Would I like to Receive Support			

Now create own!!

When you're planning, always remember:

- The person with the disability is the ultimate decision-maker
- Supporters are there to support, not supplant
- Ability to communicate needs, wishes & desires is essential – whatever the method
- Life is complex and varied consider the wide range of individual's activities, desires, aspirations, needs, plans, and so forth
- Invest the necessary time it will pay off!

Supported Decision-Making



Choose the Right Support Person/Team

Supporters should be someone you trust

Supporters may be asked to assist in areas that are very personal

The person should feel safe and know they can trust their supporter with personal information

Supporters should have knowledge

Supporters should have some knowledge or experience in the area they are asked to support

OR supporters will know who to ask and what types of questions to ask

Supporters should not be biased

Supporters should not provide advice or support based on how it will benefit them

Supporters must not act with self-interest and help advocate for the individual's choices

Information provided must be clear and accurate

You can have more than one supporter

You can have Supported Decision-Making agreements with more than one supporter

Having more than one supporter prevents people from feeling overwhelmed

Multiple supporters help prevent abuse and fraud because more people are watching

You can change your support person

Supported Decision-Making agreements are revocable

The supporter and the person with a disability can end or change the agreement anytime



Identify possible supporters

Creating a chart is a good way to keep track of possible choices

Identify possible supporters, their areas of support, how we will like their help



Possible Supporters Example

Supporter	Area of Support	How Would I Liked Them to Support Me
Charley Patton	Financial	 Assist with paying bills Assist with going to the bank Assist with paying rent on time
Bessie Smith	Medical	 Attend doctor appointments with me Assist with explaining to the doctor how I feel Assist with setting up my medication schedule
Robert Johnson	Employment	Assist with finding transportationAssist filling out applications

Supported Decision-Making



Supported Decision-Making Agreements

What Is a Supported Decision-Making Agreement?

A Supported Decision-Making Agreement is:

- An Arrangement between two people
- A Description of Responsibilities
- An Explanation of Supporter's Rights
- A Document that Helps Inform Others a Formal Relationship Exists

Why Do I Need an Agreement?

A Supported Decision-Making Agreement puts into writing <u>exactly</u> what a person with a disability expects from his or her <u>Supporters</u>.

This Agreement <u>protects the privacy</u> of a person with a disability by defining what information a Supporter is allowed to receive or see.

It also <u>lets people who provide services</u> – like doctors, lawyers, and support coordinators – <u>know that Supporters can participate</u> in appointments and decision-making.

A <u>Sample</u> Supported Decision-Making Agreement

Several Sections:

- Appointment of a Supporter
- Effective Date
- Consent of Supporter
- Signatures & Notarization

SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter _____, make this agreement of my own free will. I agree and designate that: Phone Number: E-mail address: is my supporter. My supporter may help me with making everyday life decisions relating to the following: (Yes)/(No) obtaining food, clothing, shelter. (Yes)/(No) taking care of my physical health. (Yes)/(No) managing my financial affairs. My supporter is not allowed to make decisions for me. To help me with my decisions, my supporter may: 1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records: 2. Help me understand my options so I can make an informed decision; or 3. Help me communicate my decision to appropriate persons. (Yes /No) A release allowing my supporter to see protected health

information under the Health Insurance Portability and Accountability Act of

1996 (Pub. L. No. 104-191) is attached.

	upporter to see educational records s and Privacy Act of 1974 (20 U.S.C.
Effective Date of Supported Decis	sion-Making Agreement
This supported decision-making agricontinue until (insert date) or until the supporter or me or by operation of la	
Signed this day of	, 20
Consent of Supporter	
	ct as a supporter under this agreement neaningfully participate in the life of this ndependent living.
(Signature of supporter)	(Printed name of supporter)
Signature	
(My signature)	(My printed name)
(Witness 1 signature)	(Printed name of witness 1)
(Witness 2 signature)	(Printed name of witness 2)
State of	_
County of	

	(date) by and			
(name of adult with disability)	(name of supporter)			
	Notary Public			
My commission expires:				
wy commission expires.				
	R THE ADULT WITH A DISABILITY			
WARNING: PROTECTION FOI	S A COPY OF THIS AGREEMENT OR IS OF THIS AGREEMENT HAS CAUSE TO			
WARNING: PROTECTION FOI IF A PERSON WHO RECEIVES AWARE OF THE EXISTENCE OF BELIEVE THAT THE ADULT W	S A COPY OF THIS AGREEMENT OR IS			
WARNING: PROTECTION FOI IF A PERSON WHO RECEIVES AWARE OF THE EXISTENCE & BELIEVE THAT THE ADULT W NEGLECTED, OR EXPLOITED SHALL REPORT THE ALLEGE	S A COPY OF THIS AGREEMENT OR IS OF THIS AGREEMENT HAS CAUSE TO ITH A DISABILITY IS BEING ABUSED,			

Appointment of Supporter

,	, make this agreement of my own free will.
agree and designa	te that:
Name:	
Address:	
Phone Number:	
E-mail address:	
s my Supporter. My relating to the follow	supporter may help me with making everyday life decisions ing:
(Yes) / (N	lo) obtaining food, clothing, shelter.
(Yes) / (N	lo) taking care of my physical health.
(Yes) / (N	lo) managing my financial affairs.

Appointment of Supporter (continued)

My supporter is not allowed to make decisions for me. To help me with my decisions, my supporter may:

- 1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;
- 2. Help me understand my options so I can make an informed decision; or
- 3. Help me communicate my decision to appropriate persons.
- (Yes) / (No) A release allowing my supporter to see protected health information under the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191) is attached.
- (Yes) / (No) A release allowing my supporter to see educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g) is attached.

Effective Date of Supported Decision-Making Agreement

This supported decision-making agreement is effective immediately and will continue until (insert date) or until the agreement is terminated by my supporter or me or by operation of law.

	Signed this _	day of	, 20
--	---------------	--------	------

Consent of Supporter

in exchange for the opportunity to meaningfully participate in the life of this person and the person's pursuit of independent living.

(Signature of Supporter) (Printed name of Supporter)

Signature & Notarization

(My signature)	(My printed name)			
(Witness 1 signature)	(Printed name of Witness 1)			
(Witness 2 signature)	(Printed name of Witness 2)			
State of		_		
County of		_		
This document was ackr	nowledged before me on		date by	
	and			
(name of adult with disabili	ty)			
(name of Supporter)				
	Notary	^r Public		NotaN Seal Here
My commission expires:				Ho

WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY IF A PERSON WHO RECEIVES A COPY OF THIS AGREEMENT OR IS AWARE OF THE EXISTENCE OF THIS AGREEMENT HAS CAUSE TO BELIEVE THAT THE ADULT WITH A DISABILITY IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY THE SUPPORTER, THE

SHALL REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE DEPARTMENT OF ECONOMIC SERVICES, ADULT PROTECTIVE SERVICES BY

Supported Decision-Making Agreements – Things to Remember

A Supported Decision-Making Agreement:

- Lets everyone know what is expected
- Helps protects individuals with disabilities as well as Supporters
- Tells doctors, lawyers, and other service providers that you have assistance to help make your own decisions
- Can be modified or terminated at any time

Supported Decision-Making



Less Restrictive Alternatives, Complements to SDM

Some examples of less restrictive alternatives

Powers of Attorney (General, Durable, Healthcare) Social Security – Rep Payee Vocational Rehabilitation Advocate Healthcare Planning — Living Wills Delegation of Special Education Rights

Representative payee

Payment — Management — who needs one?

Who is selected to be a rep payee?

Accounting

Roles of the Rep Payee Additional Review

Advanced directives / living wills, HCPOA

Advanced directives / living wills – instructions for future healthcare decisions

- Activates when you if you cannot communicate
- List the treatments, procedures you want
- "An adult may prepare a written statement known as a living will to control the health care treatment decisions that can be made on that person's behalf.
 The person may use the living will as part of or instead of a health care power of attorney or to disqualify a surrogate."

Healthcare power of attorney

- Use this to name an individual to make healthcare decisions for you if you become too ill to do so.
- Talk to your family and friends about your choices.

Power of attorney (general or durable)

 A power of attorney is a legal document where the principal gives another person, the agent, permission to act on their behalf in certain matters.

- The agent can make legal decisions that the principal would normally make.
- The principal should choose someone they trust. Examples could be a spouse, family member, or friend who would act in the principal's best interests.

Durable power of attorney

Some examples include buying a car, signing contracts, and making other financial decisions.

 The power of attorney form also indicates whether the power of attorney becomes effective immediately or only upon capacity.



Authorized representative in Vocational Rehabilitation

- VR provides a variety of services to persons with disabilities, with the ultimate goal to prepare for, enter into, or retain employment.
- Eligible if: (1) physical or mental impairment, (2) disability is a substantial impediment to employment, (3) require VR services to secure, retain, or regain employment, and (4) the individual can benefit from VR services

- Pre-Employment Transition Services
 - Job exploration counseling
 - Work based learning
 - Counseling on postsecondary and training opportunities
 - Work readiness training
 - Self-advocacy training

Delegation of education rights

- Students between the ages of 18-22, with capacity, does not have a guardian, can execute a delegation of right to make educational decisions.
- Otherwise, rights will transfer to the student at 18.
- Rights include: (1) re-evaluation and/or agreement to change placements, (2) receiving notices, and (3) requesting mediation.



Important links

Legal Options Manual https://www.azdisabilitylaw.org/wp content/uploads/2016/11/2016-Legal-Options Manual.pdf

 Information on the rep payee program https://www.ssa.gov/payee/

Contact Information



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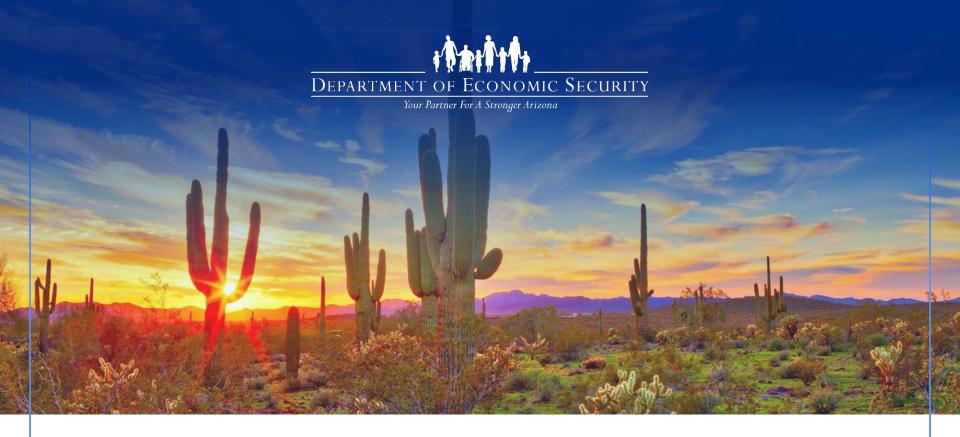
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Questions?



Thank You