

# SUPPORTED DECISION MAKING PILOT PROJECT

YOUR CURRICULUM GUIDE ON  
SUPPORTED DECISION MAKING



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# Introduction

Disabilities are a common and natural part of life. Over 50 million people in the United States are considered to have some sort of disability. That is about one out of every five people living in this country. People can be born with disabilities, gain a disability through an injury or illness, or can become disabled through old age.

Today, people with disabilities are part of our diverse communities. In school, people with disabilities receive the accommodations they need to be part of the classroom and receive the same education as everyone else. At work, accessible workstations and other accommodations allow people with disabilities to be part of the workforce. All throughout our community, accommodations can be seen to make sure we live in an inclusive community that welcomes everyone regardless of their abilities.

The advancement for the rights of people with disabilities can be traced back to the independent living and self advocacy movements of the 1960s and 70s.

People with disabilities believe:

- Disabilities are a natural part of life that do not need to be fixed.
- Society must reduce the barriers that prevent people with disabilities from being part of the community.
- People with disabilities have the right to make decisions about their own lives.

Thanks to the hard work of people with disabilities throughout the country, civil rights laws such as the DD act and the Americans with disabilities Act have brought equality and protection for people with disabilities.

The ideas first developed during the disabilities rights movement continue to ring true today. People with disabilities continue to fight for an inclusive society where they are free to choose how they want to live their lives. However, one of the areas in which this has become an issue is when families have to choose between guardianship and allowing the person with a disability to retain their rights.



For families and caregivers of people with intellectual and developmental disabilities there is a constant struggle between trying to determine how much rights and responsibilities the person with the disability is able to handle on their own. On the one hand, they would like their loved ones to be as independent as possible but on the other hand they want to make sure they are safe.

Until recently, families and caregivers of people with disabilities were given an all or nothing option when it came to the rights of their loved ones. Either they gain full legal guardianship and take away all their rights or allow them to keep their rights without having a plan to support them along the way. Furthermore, families and caregivers often had to make these decisions without fully understanding the impact it would have on the lives of their loved ones.

In line with the belief that people with disabilities should be able to make their own decisions about their lives, there is a growing movement behind supported decision-making. Unlike guardianship that takes away the rights

of people with disabilities, supported decision-making allows people to keep their rights but develops a support system around the person to assist in making life choices.

In this toolkit, we will learn about supported decision-making, how it affects the rights of people with disabilities, and how it differs from guardianship. We will also learn about the benefits of supported decision-making and how to incorporate it in the lives of people with disabilities. Finally, we will also discuss other alternatives to guardianship that can be part of the supported decision-making plan.

# What Is Guardianship?

As adults, people have many rights and responsibilities over their own lives. People are free to choose what they want to do with their lives as long as it does not take away from the rights of others. Of course, the choices made come with consequences that can affect people in a positive or negative way. Whatever the consequences may be, it is the right of that person to succeed or fail.

With that said, sometimes people with disabilities are not able to take on the rights and responsibilities given to them as adults. This can be for a variety of reasons including having an intellectual or developmental disability or from an acquired disability through an injury or as a symptom of an age-related illness. Whatever the case, for some people, guardianship may be a good option pursued by families or caregivers. As it is a choice offered by the court system, it is important to understand what is guardianship.



Under guardianship, a person or an organization is appointed by the court to make personal decisions for a minor or an incapacitated adult known as a "Ward". In Arizona, an "incapacitated adult" is someone who lacks "sufficient understanding or capacity to make or communicate responsible decisions concerning his or her own well-being."

Guardianship can be petitioned with the courts at any moment in an adult's life and can begin as early as 17 1/2 years of age. An evaluation from a medical provider must be included with the petition. The evaluation is completed using a standard court form and must include information such as a description of the person's diagnosis, his or her functional impairments and ability to form activities of daily living.

Once the court receives the petition for guardianship, a hearing is set, during which evidence of the proposed ward's level of capacity will be presented. After the hearing and weighing of evidence, if the judge finds that the person with a disability is unable to make or communicate reasonable decisions for his or her own wellbeing, the judge will declare the person with a disability as an incapacitated adult and appoint a guardian.

# Rights of a Person with a Disability under Guardianship

Under legal guardianship, people with disabilities have limited rights. Because the courts have declared the person with the disability as an incapacitated adult, they believe the person does not have the ability to make any choices for themselves. Instead, the guardian is given the responsibility to exercise their rights on their behalf as they are now responsible for the well-being of that person.

Rights taken away from people with disabilities under guardianship include:

- The right to choose their own employment
- The right to make financial decisions
- The right to live independently
- The right to vote
- The right to drive
- The right to build meaningful relationships with whoever they want
- The right to make their own health care choices
- The right to enter legal contracts

With that said, some rights may be restored to the person with a disability. Known as "limited guardianship", the person petitioning the court for guardianship can ask the judge to allow the person with the disability to keep certain rights. These rights can include the right to vote and the right to drive. In order to keep those rights, the petitioner must present evidence showing that the person is able to understand and communicate their choices.



# What Is Supported Decision-Making?

Life is full of choices. Every day we make hundreds of decisions that are big and small. We decide what to wear, what to eat, and what we need to do that day. Sometimes, people need help or support to do things or make choices. People may ask for help from friends and family on life choices like:

What to wear to a party

What to have for dinner

Buying a car

Buying a house

People with disabilities are no different from anyone else. They face the same decisions and life choices as everyone else. For some, that may be too much responsibility for them to handle on their own. In those cases, supported decision-making may be an option that can help people with disabilities keep their rights as adults while having the support they need from people they trust to ensure they are making well-informed decisions.

So what is supported decision-making? Supported decision-making is a formal network of supports around a person with a disability created to help the person make decisions and life choices. People who choose to help the person with the disability make decisions are known as supporters. In supported decision-making, supporters sign contracts promising to help the person with the disability in the areas identified by the person with a disability. These contracts are known as supported decision-making agreements. Unlike guardianship, supported decision-making does not require going to court or is assigned by a judge.

# Deciding if Supported Decision-Making Is Right for You



Supported decision-making is all about receiving the right support to live as independent as possible. When considering supported decision-making, it is important to discuss the ability of the person with a disability to communicate their wants and needs. That is to say, given the right support, can the person with a disability make decisions for himself or herself?

Of course, the person with a disability is not expected to know everything about all aspects of independent living. They are also not expected to make all the right decisions throughout their life when dealing with various issues or situations. In the beginning, the most important thing to consider when deciding on supported decision-making is the ability for the person with a disability to express their choices.

If you decide supported decision-making is the right choice to make, it is important to talk about the kind of support the person with a disability will need. Some people may be able to do certain things on their own very well but need support in other areas.

If the person chooses to live on their own, they may need support in finding an apartment or making sure they pay their rent on time.

If the person has medical appointments, they may need support in getting to their appointments on time or need support making sure they understand what the doctor is telling them.

Successful supported decision-making will need careful planning. This may require several talks that need to include the person with a disability,

families and caregivers, and perhaps even doctors or therapists. Ultimately, it is up to the person with a disability to decide what kind of support they would like in their life.

Everyone is different so no two people will have the same needs. To help think about the type of support the person with the disability will need, try creating a list. Your list should include the part of their life in which they will need support, and how they would like support.

Area of Support	How I Would like Support
Finances	<ul style="list-style-type: none"> <li>• Assist with paying my bills on time</li> <li>• Assist with managing my bank account</li> </ul>
Medical	<ul style="list-style-type: none"> <li>• Attend doctor appointments with me to make sure I understand what the doctor says</li> <li>• Assist with organizing my medication</li> </ul>
Employment	<ul style="list-style-type: none"> <li>• Assist with finding a job I will like</li> <li>• Assist with filling out job applications</li> <li>• Assist with making sure I know how to get to my job safely and on time</li> </ul>

Talking about the type of support a person will need should be an ongoing conversation because needs change over time. The person may need more support or less support as time passes.

**Activity:**

Use the chart below to identify the areas of support the person with a disability will need help in. Also, write down how they would like to receive support.

<b>Area of Support</b>	<b>How Would I like to Receive Support</b>

# Who Are Supporters?



Most people have friends and family that they can turn to for help. If they need their opinion, they can call them up and ask what they think. If they need someone to go with them to an appointment, they might go with them.

Friends and family may not always be available to provide help. They may not be able to talk and listen to problems or go to appointments. This kind of support is known as informal support. It's the type of support that may be there some of the time, but they have not made a

commitment to be there all the time.

Supporters in supported decision-making agreements are people who choose to help the person with a disability live an independent life. When a supporter signs a supported decision-making agreement, they agree to be there whenever the person with the disability needs help. This is known as a formal support.

Supporters are there to help the person with the disability in any area that person says they may need help. If the person with the disability has any questions or trouble understanding certain things, supporters are there to help them.

Supporters can help in many ways including:

- Assisting with managing finances
- Paying bills
- Filling applications or other paperwork
- Attending medical appointments
- Setting daily routines
- Explaining complicated topics in easy to understand language
- Outlining the pros and cons of decisions

These are only a few examples. How the supporter helps the person with the disability will depend on the needs of that person. Supporters can help the person in several areas of their lives or in just one area. It will all depend on what the supporter and the person with the disability feel comfortable doing.

The most important thing to remember is that supporters are there to help the person with a disability keep their independence. Supporters do not make decisions for the person with the disability or do things without their consent.

# Choosing the Right Support Person

Choosing the right support person is very important. In supported decision-making, people with disabilities choose their own supporters. They are not court-appointed or part of any agency program. When choosing a supporter, there are a few things that should be considered.

## **Supporters should be someone you trust.**

Depending on the need of the person with the disability, supporters may be asked to assist in areas that are very personal to the person with a disability. The person should feel safe and know they can trust their supporter with their personal information.

## **Supporters should have some knowledge in the area of support.**

People with disabilities may need support in several areas of their lives. It is important to choose a supporter who has some knowledge or experience in the area in which they are asked to support.



## **Supporters should not be bias.**

Supporters should not provide advice or support based on how it will benefit them. The role of the supporter is to provide clear and accurate advice and support so that the person they are helping is able to make the best decision based on their own wants and needs.

## **You can have more than one support person.**

Supported decision-making agreements can be made with more than just one support person. If a person with a disability wants, they can choose a different person for each area in which they need support. This may also be helpful for the person who is providing support by not feeling overwhelmed helping in everything.

## You can change your support person.

The person with a disability has the right to choose a different support person any time they want. Even though a supported decision-making agreement has been signed, it is not legally binding. The supporter and the person with the disability have the right to change or end of the contract anytime they want.

A good way of keeping track of possible supporters is to create a chart. Using a chart can help identify supporters and how they can help. This is only to brainstorm possible choices. Once people are identified as potential supporters, you can begin discussions to see if they would be interested in being a supporter and assisting in the areas identified. People may be able to assist in everything or only in a few things. Charts may change as you identify supporters and begin discussions in developing partnerships.

<b>Supporter</b>	<b>Area of Support</b>	<b>How Would I Liked Them to Support Me</b>
<b>Charley Patton</b>	<b>Financial</b>	<ul style="list-style-type: none"><li>• <b>Assist with paying bills</b></li><li>• <b>Assist with going to the bank</b></li><li>• <b>Assist with paying rent on time</b></li></ul>
<b>Bessie Smith</b>	<b>Medical</b>	<ul style="list-style-type: none"><li>• <b>Attend doctor appointments with me</b></li><li>• <b>Assist with explaining to the doctor how I feel</b></li><li>• <b>Assist with setting up my medication schedule</b></li></ul>
<b>Robert Johnson</b>	<b>Employment</b>	<ul style="list-style-type: none"><li>• <b>Assist with finding transportation</b></li><li>• <b>Assist filling out applications</b></li></ul>



**Activity:**

Use the chart below to brainstorm possible support people. Write down who they are, what area of support, and how you would like them to help you.

<b>Supporter</b>	<b>Area of Support</b>	<b>How Would I Like Them to Support Me</b>

# Asking Someone to Be Your Supporter

Asking someone to be a supporter is one of the most important conversations the person with the disability will have. Supported decision-making may be a new idea to the person and they may need an explanation on how it works. This first conversation provides a great opportunity to explain why they have been chosen as a possible supporter and how they can best provide that support.

Deciding to work together in a supported decision-making agreement is a big deal for the supporter and the person needing support. There may need to be more than one conversation before agreeing to work together. That is okay because there might be questions that need to be answered. The important thing is to be upfront about what is expected from each other.



When having a conversation with a possible supporter, there are a few topics that need to be discussed to make sure everyone knows what they are agreeing to do. Some things to talk about include:

## **Explain supported decision-making.**

Supported decision-making is a new idea and not everyone is going to know what it is. Talk to the supporter about how supported decision-making works and how it is different from legal guardianship.

### **Talk about the role of the supporter.**

Be clear and direct about the type of assistance the supporter will be asked to provide. Try to include as much details as possible. The supporter should have a clear understanding of the area or topic they are being asked to provide support in and how they should provide that support. Things may change as the supporter and the person with the disability work together but it is always good to have a basic idea of what the supporter will be doing.

### **Talk about the role of the person with a disability.**

In supported decision-making, people with disabilities take responsibility for their own lives. Supporters must understand that the person with the disability makes all the decisions in their lives. When talking to a possible supporter, be sure to explain to the supporter that they are there to provide assistance to ensure that independence of the person with the disability. Ultimately, it is the responsibility of the person with the disability to make their own decisions.

# Supported Decision-Making Agreements

Once the person with a disability is ready to choose a supporter, they should sign a supported decision-making agreement. A supported decision-making agreement is a formal agreement between the supporter and the person with a disability. Supported decision-making agreements turn informal supports into formal supports. By signing the agreement, supporters agree to take on the responsibility of helping the person with a disability in the areas written in the agreement. These agreements help define the role of the supporter and the person with the disability.



To be clear, these agreements are not legally binding. Supporters and people with disabilities who sign these agreements are not legally required to follow them. Furthermore, both of the supporter and the person with the disability have the right to end the agreement at any time.

Even though supported decision-making agreements have no legal enforcement, people should still take the time to create them. Supported

decision-making agreements can be provided to medical and social service providers to notify them of the role of the supporter. Some medical and social service providers may not feel comfortable providing services to a person with a disability if they believe that person is not able to understand the services they are receiving. With a supporter assisting the person with the disability, service providers may feel more comfortable working with the person with the disability.

While a supported decision-making agreement creates a formal relationship between a supporter and a person with a disability, the agreement does not give the person the right to view or receive personal records. Supporters will not have access to financial records or medical records. If the person with the disability would like their supporter to have access to personal records, they must provide the necessary paperwork to have that kind of access.

## SUPPORTED DECISION-MAKING AGREEMENT

### Appointment of Supporter

I, \_\_\_\_\_, make this agreement of my own free will.

I agree and designate that: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

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.

(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**

I, (name of supporter), consent to act as a supporter under this agreement 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**

\_\_\_\_\_

(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 acknowledged before me on \_\_\_\_\_ (date) by \_\_\_\_\_ and \_\_\_\_\_.  
(name of adult with disability) (name of supporter)

\_\_\_\_\_  
Notary Public

My commission expires:  
  
\_\_\_\_\_

**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 PERSON SHALL REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE DEPARTMENT OF DEPARTMENT OF ECONOMIC SERVICES, ADULT PROTECTIVE SERVICES BY CALLING \_\_\_\_\_ OR ONLINE AT \_\_\_\_\_.**



# Self Advocacy and Supported Decision-Making

For people with disabilities, self advocacy is the ability to speak up for oneself and communicate their wants and needs. Self advocates are the decision-makers in their lives and have the right to decide where they want to live, work, and manage their healthcare. Decisions about people with disabilities should be made by people with disabilities. In other words, "nothing about us, without us."



As the person with the disability enters into supported decision-making agreements, it is important to encourage the continued use and development of self advocacy skills. It is the ability of the person with a disability to speak up for themselves and express their needs that make supported decision-making

agreements successful. Supporters can assist by doing the following three things when working with the person with a disability:

## **Do not make decisions for the person with the disability.**

The whole purpose behind supported decision-making is to maintain the independence of the person with a disability. It is their lives and they should make their own decisions on how they choose to live. Unless the supporter has been given certain rights such as power of attorney, it is their job to ensure the person with the disability understands their choices and the consequences of their decisions. Things may not always go well but failure should not be a reason for taking away a person's rights.

## **Encourage the person with a disability to ask questions.**

The person with a disability may not always be familiar with all the topics or issues they will have to deal with in their lives. Furthermore, the person with a disability may feel intimidated and may not feel comfortable speaking up and asking questions. This can be overwhelming and may cause the person with a disability to rely on others to make decisions for them. It is important to encourage the person with a disability to ask questions when they feel that they do not understand something or if things are a bit too difficult. It is the role of the supporter to ensure the person with a disability understands what is being asked of them to the greatest extent possible so that they are able to make well-informed decisions.



## **Take your time to explain concepts and tasks in an easy-to-understand manner.**

Perhaps one of the most important parts of supported decision-making is the communication between the supporter and the person with a disability. How the supporter talks to the person they are assisting and explains the concepts will determine the success of their partnership.

Each person will be different, but in general, supporters should use accessible language when explaining things or helping the person with a disability to make a decision. That is to say, supporters should avoid using large words that are not commonly used. If there are words or technical

terms that need to be used, supporters should take the time to define them and explain what they mean.

Supporters should also break down information and tasks into small easy to understand and do steps. Providing a person with a disability with large amounts of information all at one time may be overwhelming and cause confusion or unneeded duress. By breaking down information into small steps, the person with a disability is able to take their time to understand what is being said and have the ability to ask questions if they do not understand.

Encouraging the person with a disability to advocate for themselves and to learn about the issues and topics that affect their lives is a benefit to everyone. The person with a disability will feel more confident in making decisions for themselves and may rely less on the need for their supporters. Furthermore, it also increases the safety of the person with a disability who will be more capable of recognizing when someone is trying to take advantage of them or not honoring their decisions.

# Complements to Supported Decision-Making

Supported decision-making is a great way for people with disabilities to maintain their rights while having a support network around them to assist them in making decisions. Unlike guardianship, people who use supported decision-making keep their rights along with maintaining full responsibility for their decisions.

While supported decision-making is a great alternative to guardianship, some people with disabilities may not be ready to take on all their newly gained rights and responsibilities as adults. Some people may not be ready to handle their own finances or feel ready to make medical decisions for themselves. This does not mean that guardianship should be pursued. People are different and everyone may have different needs at different moments in their lives.

The following programs and services serve as complements to supported decision-making. They are broken down into three categories that include medical, financial, and educational. These are three of the main areas that affect people's lives on a daily basis. However, much more information can be found by visiting the Arizona Center for Disability Law website and downloading their legal options manual. Visit the website by clicking on the following link:

<https://www.azdisabilitylaw.org/guides/#legal-options>

## **Complements to Supported Decision-Making**

### **Financial**

- **Representative payee**
- **Durable power of attorney**
- **Conservator**
- **Trust**
- **Able accounts**

### **Medical**

- **Advance directive**
- **Durable medical power of attorney**
- **Durable mental health care power of attorney**
- **Living will**

### **Education**

- **Delegation of right to make educational decision**

## **Representative Payee**

### **Who needs a representative payee?**

For people with disabilities whose only get money from Social Security, they can have a representative payee assist in managing finances.

### **What does a representative payee do?**

A representative payee receives Social Security benefits on behalf of a beneficiary for the purpose of managing these benefits. Specifically, the representative payee must:

Use the payments only for the use and benefit of the beneficiary such as:

- payment for rent
- medical expenses
- food
- clothing
- savings

Tell SSA of any event that will affect the amount of benefits the person should receive (such as an inheritance or earnings)

Send SSA, upon request, a written report accounting for the benefits and maintain good records of the moneys spent, saved or invested for the beneficiary

Notify SSA of any change in circumstances which would affect the representative payee's performance (such as payee's illness or a change in relationship to the beneficiary).

The SSA also publishes "A Guide for Representative Payees" (Pub No. 05-10076) and "When a Representative Payee Manages Your Money" (Pub No. 05-10097) available on the Internet at [www.ssa.gov/pubs](http://www.ssa.gov/pubs) or by calling toll free at 1-800-772-1213 (voice) or 1-800-325-0778 (TTY).

## **Durable Power Of Attorney**

### **Who needs a durable power of attorney?**

An individual who is of sound mind (legally competent) and who wants to select someone else to act as his or her agent, to make financial decisions on behalf of the person, could benefit from a durable power of attorney.

### **What does an agent under the durable power of attorney do?**

A durable power of attorney document is a document that allows one person, the principal, to give someone else, the agent, the authority to handle his or her financial affairs now, or at some designated time in the future. For a durable power of attorney to be valid, the principal who designates the agent must be able to understand and give consent for another person to handle his or her financial affairs at the time the power of attorney is signed. The durable power of attorney may specify what financial decisions the principal wants the agent to make. For example, the power of attorney could be limited to paying bills, or could be permitted to handle all financial decisions for the principal. The power of attorney also indicates whether it is effective immediately or only upon incapacity of the principal.

Unlike a conservatorship, there is no court oversight of a durable power of attorney. This means the agent does not have to report expenditures to the court on a regular basis. However, an agent may be criminally prosecuted if he or she does not use the money or property for the benefit of the principal.

## **Conservatorship**

### **Who needs a conservatorship?**

Individuals who are not capable of managing their finances and who own property or have income or other assets may benefit from a court-appointed conservator. A conservator acts as a person's financial manager, appointed to oversee all the person's assets and property. If a person's only income is from SSI or SSDI, a representative payee designation may be more appropriate than a conservatorship.

### **What does a conservator do?**

A conservator manages the protected person's money and property. A conservator must take responsibility for determining what money and property a protected person has, where the money and property is located, what measures are needed to preserve certain assets, and how long these assets can be expected to maintain the protected person. If the protected person owns a house, the conservator must be certain that the house is insured and property taxes are current, and that the protected person is able to afford upkeep on the house. The conservator pays the protected person's bills with the protected person's money. The conservator may need to make investment decisions on behalf of the protected person.

Unless the protected person's assets are in a "restricted" account, the conservator must file with the court, as well as share with all interested persons an accounting that reflects all transactions made on behalf of the protected person. The court accepts accountings only on certain approved forms, which are available on the probate court's website for the county where the conservatorship originated



## **Trust**

### **Who needs a specialized trust?**

A person who wants to maintain financial eligibility for government programs such as Social Security and who also has funds available from some other source may benefit from a specialized trust. Because eligibility for certain government programs depends on a person's income, a trust allows for certain monies to be set aside for a person, or the beneficiary of the trust, to be used for certain purposes. The money that goes into the trust could be from an inheritance, settlement or money that a beneficiary's friend or family member wants to set aside on his or her behalf.

### **What does a specialized trust do?**

A specialized trust includes parameters about what the trust money can and cannot be spent on. By including these limitations, the trust allows for the beneficiary of the trust to receive disbursements from the trust for certain purposes without jeopardizing a beneficiary's eligibility for certain government programs.

## **Able Accounts**

### **What is an ABLE account?**

The ABLE (Achieving Better Life Experience) Act is federal legislation that allows persons with disabilities (recognized by age 26) and their family members to create tax-free savings accounts called ABLE accounts. The Act came into existence in 2014 and several states immediately established programs to administer ABLE accounts. Arizona's version of the ABLE Act was signed into law in May 2016 and should become effective no later than July 2017.

ABLE accounts, unlike regular bank accounts, may hold more than \$2,000 and will not disrupt eligibility for public benefits for persons with disabilities. In addition, it appears that ABLE accounts for persons with disabilities, even those who receive 'need-based' benefits such as SSI and ALTCS, may be used for such things as housing, personal support services, medical care, assistive technology, and transportation. So ABLE accounts offer greater flexibility than Special Needs Trusts. ABLE accounts should be less expensive to establish and easier to manage than Special Needs Trusts.

## **Designated Representative in Mental Health Care**

### **Who needs to designate a mental health representative?**

Any person who receives public mental health benefits from a Regional Behavioral Health Authority (RBHA) or a RBHA member is entitled to have a designated mental health representative to represent the RBHA members' interests. Any RBHA members who want representatives to make mental health treatment and planning decisions can designate a mental health representative at anytime.

### **What does a mental health representative do?**

A mental health representative is designated by a RBHA member to help protect the member's rights and voice their service needs. The RBHA must provide the designated representative with written notice about the date, time, and location of meetings about inpatient treatment, discharge planning, and other service planning. The designated representative may go to service and discharge planning meetings, help fill out grievance and appeal forms, and attend meetings, which are informal conferences and administrative hearings related to the appeals process.

## **Health Care Advanced Directive/ Durable Health Care Power of Attorney**

### **What does the health care advanced directive do?**

This option allows individuals to choose a representative to make decisions about health care and basic needs if they become unable to make or communicate those decisions for themselves. The representative who makes the decisions is known as the “agent” or “representative.” The individual who chooses an agent is the “principal.” Once appointed, the agent will make and communicate decisions about the principal’s health care or basic needs only if they become unable to make those decisions for themselves. The document can provide specific direction to the agent regarding the principal’s wishes for his or her future health care decisions.

The representative will have the authority to make health care decisions consistent with the principal’s wishes in the event the person signing the document becomes incompetent. The principal may revoke this document in full, and change agents and/or add other agents at any given time.

## **Mental Health Care Advanced Directive/Durable Mental Health Care Power of Attorney:**

### **What does a mental health care advanced directive do?**

This document allows an individual to appoint a representative who can admit the individual to a behavioral health facility in the event the individual needs such treatment. The directive may also include preferences for mental health medication and treatment.

## **Living Will**

### **What does a living will do?**

A living will lists the treatments, procedures or interventions that a person wants as well as those he or she wishes to refuse. Living wills are often used at the end of life when that person can no longer state his or her preferences. The living will covers situations such as when to resuscitate and when to use a feeding tube, ventilator or other extraordinary measures to prolong a person's life.

## **Delegation of Right to Make Educational Decision**

### **Who can benefit from delegating the right to make educational decisions?**

When students become 18 years old, the right to make decision about their special education services is transferred to them because they are adults under the law. The exception to this rule is when students become 18 years old and a court has determined that they need a guardian because they do not have the capacity to make their own decisions. When there is no guardianship, high school students between the ages of 18 and 22 receiving special education services, but who want their parents to make educational decisions, may benefit from having a representative. The student must be able to give informed consent for the representative's involvement.

### **What does a transfer of educational decision-making rights do?**

When a student with a disability reaches age 18—no longer a minor in the eyes of the law—all parental rights under special education laws become the rights of the student, unless he or she is under guardianship. Transferring these rights to someone else allows another person to make educational decisions on behalf of the student.

If a student wants his or her parent or another trusted adult to attend IEP meetings, take notes, and provide support to help the student to make his own decisions, he or she may invite the parent to the IEP meeting. Inviting parents to support students in their decision making does not require a transfer of educational rights.