

2018

Alternatives to Guardianship Toolkit



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University of Montana Rural Institute for
Inclusive Communities,
A Center for Excellence in Disability
Education, Research, and Service

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About the Rural Institute for Inclusive Communities

The Rural Institute for Inclusive Communities is one of 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the U.S. Administration for Community Living. It is an inter-disciplinary organization that promotes full participation in rural life for individuals with disabilities. The Rural Institute accomplishes this goal by engaging in research, providing education and interdisciplinary training, and developing model services that improve the skills, abilities, quality of life and satisfaction of people with disabilities in rural communities, their families and those who serve and support them.

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About Children's Special Health Services

Children's Special Health Services (CSHS), is charged by the Federal Maternal Child Health Bureau to: "Support development and implementation of comprehensive, culturally competent, coordinated systems of care for children and youth who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

Children's Special Health Services

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We welcome your suggestions for changes and additions to the Alternatives to Guardianship Toolkit. Please send your feedback to:

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Alternatives to Guardianship Toolkit

Do you know you have options?

For many families who have a child with a disability, the topic of guardianship will come up at some point. Are you aware your family has options or alternatives to guardianship? This toolkit is designed to help you become aware of options you can consider. While the toolkit was developed for Montana youth and families, much of the information will be relevant for young people across the country.

What are the alternatives to guardianship?

There are many tools that can ensure a young person remains at the center and an active part of decisions as they become an adult. We will review these tools in a least restrictive to more restrictive order, based upon what is needed by an individual. The alternatives can be as simple as including specific language in documents and using supported decision-making, or as complex as establishing partial guardianships. We will explore different tools for the areas families tell us are most important, including: education, medical, and financial. We will also look at topics such as Powers of Attorney.

Why consider alternatives to guardianship?

“Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings” (National Guardianship Association, 2015, p.2).

As stated by Jameson et al. (2015), “Research has consistently shown that people with disabilities who exercise greater self-determination have improved employment and quality of life, are better problem solvers, and are better able to resist and avoid abuse” (p. 3).

Basically, it is the right thing to do. People who have the opportunity to make their own decisions experience better employment outcomes, become more independent, and are more integrated into their communities.

Montana law requires it!

According to Montana Code Annotated Section 72-5-306:

Guardianship for an incapacitated person may be used only as is necessary to promote and protect the well-being of the person. The guardianship must be designed to encourage the development of maximum self-reliance and independence in the person and may be ordered only to the extent that the person's actual mental and physical limitations require it. (2017b, para. 1)

How do we develop maximum self-reliance and independence? How do we determine what is required based on an individual's needs? Outside of considering guardianship, what else have we tried in order to support the person? What opportunities have we provided to help them

develop necessary decision-making and life skills? In the pages ahead, we will look at tools to assist in identifying what an individual may need, and options for meeting those needs.

When do alternatives to guardianship need to be developed?

Start early with a conversation about what supports will be needed and how to provide them in the least restrictive way possible. This allows time for you to develop the tools, and most importantly allows time for the individual being supported to understand the tools and how they will be used. Also, time may be needed for the individual to develop a signature and receive training in what to sign, when to sign, and how to respond to pressure about signing a document. For youth, the tools will not go into effect until they become an adult at age 18 and can legally sign the document(s).

Additional Resources

Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities
<http://journals.sagepub.com/doi/pdf/10.1177/1540796915586189>

National Center on Secondary Education and Transition
Research to Practice Brief, Self-Determination: Supporting Successful Transition
http://www.ncset.org/publications/researchtopractice/NCSETResearchBrief_2.1.pdf

Preparing for Alternatives

It is never too early or too late to start preparing for the “nexts” in life. When a youth and their family are considering what tools could provide them the support wanted and needed in decision making, it is important to include the opportunity for growth. A question you may want to ask yourself is, “Has this young person been given the chance to develop the skills they will need as an adult? If not, how can we help them develop those skills now?”

Sometimes we view tasks as “too difficult to understand or deal with” and so we don’t provide opportunities for growth or next steps in skill development. In order for young people to become more independent, we need to intentionally explore what they are able to do and what they will need to be able to do. We need to encourage youth to test new skills, take risks, and learn from mistakes (“what might I do differently next time?”). We need to teach them how to evaluate options and to trust in themselves as being capable.

Opportunities for choice and decision-making occur naturally. Do we provide the time needed to invest in these as learning experiences? Can we create additional scenarios that will help the person develop and practice new skills?

Getting to Know the Individual Being Supported

- What are their current skills and strengths?
- What skills need strengthening?
- What are the concerns of those who provide support or assistance?
- What are the fears?

One of the many benefits to using alternatives to guardianship is that the tools can easily be adjusted to meet the evolving needs of an individual. If skills or primary support people change, the tools can be updated to continue assisting the person without requiring action by a court or judge.

You might even consider including a “growth clause” in the tools you develop. Here is sample language:

My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it should be changed or cancelled at least every _____. However, unless my agent and I change the [Power of Attorney/Advanced Directive/Plan], I cancel it, my agent resigns, or either I or my agent dies, the [Power of Attorney/Advanced Directive/Plan] will continue.
(Martinis, 2016)

Additional Resources

American Bar Association

PRACTICAL Tool

http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

Autistic Self Advocacy Network

The Right to Make Choices: International Laws and Decision-Making by People with Disabilities, Easy Read Edition, Part 2: Supported Decision-Making

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-2-Supported-Decision-Making-v3.pdf>

Got Transition

Guardianship and Alternatives for Decision-Making Support

<http://www.gottransition.org/resourceGet.cfm?id=17>

Wisconsin Community of Practice on Transition Practice Group on Health

Transition Health Care Checklist: Preparing for Life as an Adult

<http://www2.waisman.wisc.edu/cedd/wrc//pdf/pubs/THCL.pdf>

Supported Decision-Making

What is supported decision-making?

Supported decision-making (SDM) is an alternative to guardianship. SDM is rooted in the belief that all people have the right to make choices and decisions about their own lives. Although SDM may involve different forms and processes, the key is that the individual who will be directly impacted is supported to make a decision based on their needs, wants and preferences. With SDM, we may use different formats to fit the individual and the situation. The individual chooses who to involve (such as friends, a family member or professional) to help them understand information, including the impact of different choices and what options should be considered before making a decision. Does this sound familiar? It is the same process many of us use regularly to make a decision or choice if we do not have the information we need to move forward.

Supported decision-making is voluntary for the individual. How the process looks or is used will vary based on the person and the decision to be made. SDM could mean one-to-one assistance or it could involve bringing together a group of people chosen by the individual based on the specific information they bring to the table. For example, a person may not need a mechanic to help with meal planning but if their car breaks down, someone they trust who knows more about cars will be the first person they contact for support. If they need help figuring out how to pay for the vehicle repairs and arranging other transportation while their car is in the shop, people with information to share in these areas might participate as well.

SDM can look like person-centered planning, and the person-centered planning format can be used if it will benefit the individual making the decision. What is most important is that the person is given the opportunity to understand information they need in order to make their decision, and that the information is communicated in a way that supports their understanding. They may also choose to have help in communicating their choices. The goal is for the individual to retain control of their life and choices to the maximum extent.

How does supported decision-making work?

First, talk with the individual about who they would like to have support them in making decisions. Work together to answer the questions below:

- What skills do the support people have?
- How can these support people assist in making decisions?
- Will it be a group or one person? (What is the preference of the individual?)
- Will selected people help with specific types of decisions?

Next, think about the current choice or decision the individual being supported needs to make.

- Does the individual need help understanding information?

- Do they need help expressing their choice?
- When does the decision or choice need to be made?

Finally, develop an informal or formal plan. Share the plan with others who will need to know the wishes of the individual being supported.

Additional Resources

National Resource Center for Supported Decision Making – resources include:

Welcome Message

<http://supporteddecisionmaking.com/sites/default/files/NRC-SDM-Welcome-message.pdf>

Supported Decision-Making Model Agreements

<http://www.supporteddecisionmaking.org/node/390>

Brainstorming Guide

<http://www.supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

Supported Decision-Making Teams: Setting the Wheels in Motion

<http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

Introduction and Guide to Supported Decision-Making YouTube Video Series

<http://supporteddecisionmaking.org/node/432>

Education

For some families, the discussion of guardianship first comes up within the area of education. The Individualized Education Plan (IEP) requires “Transfer of Rights” paperwork to be completed at least one year before a youth turns 18. Many times, schools fill out the transfer paperwork sooner to help youth and parents plan for the change in who will be making decisions.

Support Options in Order from Least Restrictive to Most Restrictive

No Added Supports

At age 18, the student will now make all educational decisions. Hopefully, within the Transition process, activities have been provided to help the young adult develop their decision-making skills. Parents still receive notice of all Evaluation Team and Individualized Education Program meetings.

The student could invite a parent to participate as part of the IEP team (as a “person with specialized knowledge”) but it is now the student’s right to sign their approval for the IEP. Using a supported decision-making model, the young adult could consult with trusted team members about any needs or concerns they have about their educational plan before signing their agreement to the IEP. The young adult’s signature of agreement or identification of concerns needs to be discussed with the school district in a timely manner, and preferably in less than two weeks.

A final item to consider is when a school district asks for consent for an adult student to participate in activities. If the student is over the age of 18 and they do not have a legally appointed guardian, the parents should no longer state that they assume financial liability.

Additional Support

The young person may feel they need more support in a meeting. They may not be practiced or comfortable in signing contracts, such as their Individualized Education Plan. A possible next step would be to develop an **Educational Advocacy Form**, including a **Consent to Release Information** that states the young adult wants a specific individual at their meetings and to assist them in understanding information that requires their signature. The advocacy form could include language that the young person would like their advocate to sign the IEP (in addition to themselves).

These documents should be written in language the young person can understand and should include components they feel are important for their success. The student will likely need

support to learn what the tool is, what it can and cannot do, and how to use it. They may also need to learn and practice what a signature means and how to be safe about signing documents.

Please see the appendices for sample Educational Advocacy Form language.

Educational Power of Attorney

If the young person needs more support than the advocacy form can provide, a next step to consider is an **Educational Power of Attorney (POA)**. An Educational POA allows the young adult to appoint someone to make decisions for them concerning their education and IEP rather than with them. For more information, as well as sample language for adding a supported decision-making component to a POA, please see the *Powers of Attorney* section later in this guide.

Limited Guardianship

The last tool prior to a full guardianship would be a limited guardianship. Montana Code Annotated 72-5-320, provides guidance on establishing a limited guardianship:

Purposes for establishment of limited guardianship. A petition seeking the establishment of a limited guardianship must specify the particular powers that the limited guardian is proposed to exercise and the particular areas of protection and assistance required. The purposes for which a limited guardian may be appointed include:

- 1) to care for and maintain the alleged incapacitated person;
- 2) to assert and protect the rights and best interests of the alleged incapacitated person;
- 3) to provide timely and informed consent to necessary medical procedures and procedures implemented in connection with habilitation and training programs;
- 4) to assist in the acquisition of necessary training, habilitation, and education for the incapacitated person;
- 5) to exercise any other powers, duties, or limitations in regard to the care of the incapacitated person or the management of the person's property that the petition explicitly specifies, which may not be greater than the powers a full guardian may exercise.

History: En. Sec. 7, Ch. 344, L. 1981; amd. Sec. 2408, Ch. 56, L. 2009.

Considerations for Post-Secondary Education

Adult education settings will expect the student to make their own decisions and handle all their school-related responsibilities. However, if the young adult chooses to have help, arrangements can be made. What is recognized and used in each educational setting can vary; ask what tools the institution has available to support the young person with decision-making.

Do they have forms for the sharing of financial, academic or medical information? If more support is needed, consider one of the other tools described earlier in this section.

Additional Resources

Disability Rights Montana

Students Rights: A handbook to the Educational Rights of Students with Disabilities in Montana

<http://disabilityrightsmt.org/janda3/files/home/Buttons/2016.08.31%20Student%20Rights%20Handbook.pdf>

Montana Office of Public Instruction

Transfer of Rights-Parent Notice

<http://opi.mt.gov/Portals/182/Page%20Files/Special%20Education/Forms/Transfer%20of%20Rights%20-%20Parent%20FINAL%209-5-17.pdf?ver=2017-09-05-123059-280>

Transfer of Rights-Student Notice

<http://opi.mt.gov/Portals/182/Page%20Files/Special%20Education/Forms/Transfer%20of%20Rights%20-%20Student%209-5-17.pdf?ver=2017-09-05-123059-280>

Medical

Many variables affect how prepared a young person is to take over their healthcare. Are they aware of what their medical diagnosis is and how it impacts their daily life and activities? Have they been a part of the conversation, or just informed about what they need to do and when they need to do it? How much do they know about their medications and medical specialists specific to their needs? Below in the *Additional Resources* section, you will find several tools to promote conversations about medical needs and to identify strengths.

In addition to becoming more knowledgeable about their healthcare needs and having the opportunity to practice related skills, what supports are available if a young person would like assistance?

Support Options in Order from Least Restrictive to Most Restrictive

No Added Supports

At age 18, the young person will now be in charge of their own medical care. This includes having the responsibility to make and attend appointments, fill prescriptions, take medication as needed, etc. It also includes having the right to access their medical records. Young adults may need assistance to navigate the system and understand information.

Practicing these skills can add to an individual's personal toolbox. By using a supported decision-making model, for example, an individual can have someone with whom to review their concerns and questions before going to a medical appointment. Who is their "go-to" person for medical advice? Has the young person identified who they trust to support them with healthcare matters? This support person could practice tasks with the young adult such as making an appointment or refilling a prescription. They might even attend a medical appointment with the young adult to help share and ensure understanding of information. This, in turn, may lead to the use of other tools.

Technology

Have we considered what technology might be available to assist with independence? How might the cell phone the young person carries be used to address some of the challenges they face? There are a multitude of "apps" as well as low-maintenance technology that could be used to provide support in areas such as:

- Medication or appointment reminders
- Notetaking for communication or items to be shared with the doctor
- Monitoring exercise, sleep and blood sugar levels

MonTECH is a statewide resource for anything to do with Assistive Technology. Visit their website for more information: <http://montech.ruralinstitute.umt.edu/>

Lay Caregivers

In 2017, the Montana Legislature passed a bill that allows for the designation of lay caregivers by a patient, upon admittance to a hospital and before discharge. Designated caregivers can be natural supports such as family or friends. The hospital must have a process for receiving written consent from the patient to release medical records and information to the caregiver. Designated caregivers are to be provided information such as discharge plans and needed support for the patient upon returning home. For more information, please refer to Montana Code Annotated Title 50, Chapter 5, Part 7:

http://leg.mt.gov/bills/mca/title_0500/chapter_0050/part_0070/sections_index.html

HIPPA Release and Supported Decision-Making Tool

In order to have someone else in the room when medical information is shared, the healthcare professional may require a **HIPPA (Health Insurance Portability and Accountability Act of 1996) Release** be signed. This release should also be required if the young person wants their medical provider to be able to speak with their identified health care supporter(s) over the phone.

To create a supported decision-making tool, language can be handwritten onto the HIPPA release form. For example, “and for decision-making purposes” (Martinis, 2016) may be written onto the release prior to the individual signing it.

Medical Advocacy Form

Another tool that can be used to identify who is supporting the young adult and explain the role of the advocate is a **Medical Advocacy Form**. This tool may be helpful for someone who struggles with communication and wants their advocate to be able to share their choices with others. Although the form is not considered a legal document, it has been successfully used to support individuals. Sample language for a medical advocacy form can be found in *Appendix B*. An important feature of this tool is that it focuses on working with the individual needing support. A supported decision-making tool may also be used to share who the identified support person is and how they will help the individual understand medical information and make choices. Please refer to the *Supported Decision-Making* section and sample forms.

Medical Power of Attorney

If the young person feels they would prefer to have a legal document to share who their support person is and the role of that person, they can use a **Power of Attorney (POA) for Medical**. It is important to understand a POA gives another person the ability to make choices

for an individual. Language can be added to a POA to use it as a supported decision-making document. Please see the *Power of Attorney* section later in this guide for more information.

Advanced Directives

According to the Montana Department of Justice:

Advance health care directives provide instructions about the level of health care someone wants or does not want in the event that they become seriously ill and unable to speak for themselves. Advance directives can be short, simple statements expressing someone's values and choices. Advance directives are not used as long as an individual is able to express his or her own decisions on whether to accept or refuse medical treatment. They are used only when an attending health care provider determines that someone is in a terminal condition and is no longer able to participate in making decisions regarding medical treatment. (Montana Department of Justice, 2017)

Including language such as that below would allow an individual to use the medical advanced directive with a supported decision-making component:

My agent will work with me to make decisions and give me the support I need and want to make my own health care decisions. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make health care decisions for me, my agent will provide support to make sure I am able to make health care decisions to the maximum of my ability. (Martinis, 2016)

Montana Mental Health Advanced Directives

According to Disability Rights Montana:

With the creation of advance medical care directives being so popular, people are also asking if they need a **Mental Health Care Advance Directive** to document their wishes for treatment and care in the event that they become incapacitated through a mental illness. The purpose of the *Mental Health Care Advance Directive* is to 'promote more timely, informed, compassionate, and effective mental health care,' among others. Disability Rights Montana has created a form and instructions to assist people who experience mental illness to prepare for the possibility that they may become unable to express their own wishes regarding their care and treatment. A *Mental Health Care Advance Directive* provides the legal authority for provision of mental health care during a period of incapacity, even over the person's own protests. (Montana Mental Health Care Advanced Directive, 2017)

Instructions and a copy of the form can be found here:

<http://disabilityrightsmt.org/articles-advance-directives-57>

Additional Resources

The Rural Institute for Inclusive Communities, Transition and Employment Projects

Planning Your Transition from Pediatric to Adult Health Care: A Workbook to Help You Take Charge of Your Health

http://ruralinstitute.umt.edu/transition/Handouts/Planning_Your_Transition_from_Pediatric_to_Adult_Health_Care_Workbook-2014.rev1.docx

ASAN, Autistic Self Advocacy Network

Transition to Adulthood: A Health Care Guide for Youth and Families

<http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>

American Bar Association

Giving Someone a Power of Attorney For Your Health Care

http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_hcdec_univhcpaform_4_2012_v2.authcheckdam.pdf

Office of Developmental Primary Care

Supported Health Care Decision-Making

<http://odpc.ucsf.edu/supported-health-care-decision-making>

Montana Department of Justice

End of Life Registry and Advanced Health Care Directives

<https://dojmt.gov/consumer/end-of-life-registry/>

My Choices Advance Directive

<https://media.dojmt.gov/wp-content/uploads/F-My-Choices-Advance-Directive.pdf>

Montana State University Extension

Montana's End-of-Life Registry

<http://msuextension.org/publications/FamilyFinancialManagement/MT200602HR.pdf>

Financial

Families and schools may have started working to develop financial literacy skills while the individual was young. Schools often start with money management by teaching students to identify coins and their values. But what if the student was unsuccessful at this task? Did we look for another way to build their skills? For example, if the student could not identify the value of coins, were they given the chance to learn the “dollar over” concept? Did they buy items in their community? At home, did the young person receive an allowance or earn money doing chores or odd jobs? Did they choose how to spend their money? Did they learn how to save money for larger purchases? Have they ever held a job? Paid employment can help build money handling and management skills.

To determine what supports a young person needs, start with a survey of what skills they already have, what they will need to be able to do, which skill levels can be increased, and which areas will likely need longer-term support. Remember that support needs can change over time as people practice and learn.

Please see the *Additional Resources* section for a sampling of tools to increase money management skills.

Support Options in Order from Least Restrictive to Most Restrictive

Minimal Assistance

If the young adult wants to open an account or has financial questions, they can ask a support person to go with them to their bank to ensure language is used that they understand. The support person can also help plan for what is needed prior to going to the bank, or even assist with a phone call to ask will be needed at the visit.

Using direct deposit of income can eliminate the need to go to the bank in person. Many employers, Social Security, and government agencies offer direct deposit as an option. Smartphone apps can be used to make bank deposits. If technology is a strength for the young person, this might be a way for them to conduct their banking with minimal support. For individuals who use computers to access their accounts or conduct online banking, automatic bill paying may be available. This can ensure that monthly bills are paid on the appropriate dates. With certain bill paying apps, users can check scheduled payments or even make a new payment, depending on what the app allows.

For a young person paying cash, if they are using the “dollar over” method and need support in the community, they can carry a bill-sized number line in their wallet to help them determine

the amount to pay. If cash is a challenge, the individual might use a debit card with set amounts available. These cards can be linked to bank accounts for online/app monitoring. Prepaid gift cards, either for specific stores or for general use (such as pre-paid credit cards) can also be useful tools, though it is important to note that not all businesses accept card payments.

More Support through Restrictions

Additional supports can be used if the young person wants and needs more assistance with their bank accounts. For example, the individual might use a joint account. This is where the individual and the person who assists them are both listed on the account. Both parties have equal access to information and funds, so it is important that the young adult trusts the support person and that they both understand their responsibilities. Another option is to open a dual signature account for all checks or for those over a specific dollar amount.

Monitoring the amount of money available in an account or linked to a card is another way to ensure deposits are enough to meet the expectations and budget of the individual. Or the young person might open separate accounts for deposits and bill paying, daily purchases, and saving for larger purchases.

Lastly, the young person can pay a money management service to assist with bill paying, tracking how money is spent, and building financial literacy skills.

Important note: Please consider asset limitations if the individual receives government assistance such as Supplemental Security Income (SSI). Later in this toolkit, we will share ideas for saving larger amounts of money in order to support greater independence.

Representative Payee

If an individual receives Social Security and/or SSI and wants help learning to manage their money, a representative payee can be appointed to assist. The Social Security Administration will require paperwork to be completed first. The representative payee can be someone supporting the individual, such as a family member or friend. If that is not possible, an organization may provide this service. The representative payee is responsible for completing an annual report to show how the monthly income was used to meet the basic needs of the Social Security/SSI recipient.

Financial Power of Attorney

If the young person needs more support or has multiple financial resources, a next step to consider is a **Financial Power of Attorney**. A Power of Attorney (POA) allows the young adult to appoint someone to make decision for them concerning their finances, rather than with them. Please see our section on *Power of Attorney* later in this toolkit.

Trusts

Special Needs Trusts can be used to help an individual manage larger amounts of money that could otherwise impact their eligibility for means-tested programs. There are different types of trusts. Considerations when choosing which trust is best for an individual may include: Who is contributing the money to the trust; whether or not the individual with a disability will have direct access to the funds; and what the funds will be used to purchase. We strongly recommend finding an experienced professional to assist in the language and establishment of any trusts.

Conservatorship

Conservatorship is a court-ordered process in which one person (the conservator) is appointed to manage another person's finances and property. A conservatorship is similar to a limited guardianship in that it limits what the conservator manages. The court assigns the responsibilities and duties of the conservator; these are intended to be in the best interest of the person being supported.

ABLE Accounts

ABLE (Achieving a Better Life Experience) accounts were created through Federal legislation in 2014. In Montana, the 2015 State Legislature authorized the Montana ABLE program, which officially became available in September 2017. An ABLE account allows a qualifying individual with a disability to have savings set aside up to allowable amounts, without impacting Social Security and Medicaid. Savings can then be used for qualifying disability-related expenses. An individual can only have one ABLE account and the person who benefits from the account is considered the owner of the account. Montanans who need support in managing their ABLE account can complete the **Montana ABLE Agent Authorization/Power of Attorney** form, available at <https://cdn.unite529.com/jcdn/files/UABLE/pdfs/mt-poa.pdf>.

To learn more about Montana ABLE or to open an account, visit the official website:
<https://savewithable.com/mt/home.html>

For Montana-specific information about ABLE accounts, visit the Montana Department of Public Health and Human Services website at:
<http://dphhs.mt.gov/dsd/developmentaldisabilities/ABLE>

For national information about ABLE accounts, visit The ABLE National Resource Center website at: <http://www.ablenrc.org/>

Additional Resources

Montana State University Extension

Estate Planning for Families with Minor and/or Special Needs Children

<http://msuextension.org/publications/FamilyFinancialManagement/MT199117HR.pdf>

Power of Attorney

<http://www.msuextension.org/publications/FamilyFinancialManagement/MT199001HR.pdf>

Center for Parent Information and Resources

Getting Ready for Managing Finances at the Age of Majority

<http://www.parentcenterhub.org/repository/aom-series-finance/>

Social Security

Representative Payee

<https://www.ssa.gov/payee/>

Pennsylvania Assistive Technology Foundation

Cents and Sensibility: A Guide to Money Management for People with Disabilities

<http://www.fliconline.org/documents/patffinancialeducationbooklet-final.pdf>

Life After IEPs: It's Your Child's Future

Tools for Teaching Financial Literacy Skills

<http://lifeafterieps.com/tools-for-teaching-financial-literacy-skills/>

ABLE National Resource Center

ABLE Accounts: 10 Things You Should Know

<http://www.ablenrc.org/about/what-are-able-accounts>

Power of Attorney

Formal Supports

Power of Attorney (POA) is a more restrictive tool and involves a legal process. A POA can be limited to one area or cover several, depending on the needs of the individual. Because the POA is a legal document, the language that must be used can be difficult for the individual being supported to understand. We recommend that you have an attorney, at minimum, review the draft document to ensure the proper use of terms based on the purpose of the POA.

As we mentioned earlier in this toolkit, a Power of Attorney appoints a person or agent to act for the individual, rather than with the individual. One way to bring the individual back into the role of a participant, is to consider adding a supported decision-making component to the POA. Here is sample language for including supported decision-making:

It is my and my agent's intent that we will work together to implement this Power of Attorney. That means that I should retain as much control over my life and make my own decisions, with my agent's support, to the maximum of my abilities. **I am giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions.** (Martinis, 2016)

The Power of Attorney in Montana statute under the Uniform Power of Attorney Act was passed, in part, to allow for more consistency across states that had a uniform code for Power of Attorney, as well as to make the tool easier to use. The Montana Act deals with the financial support needs of an individual. This support may be for personal finances, property, or overseeing benefits the individual may be eligible to receive. More information, including the requirements for all parties, is written out in the law and available here:

http://leg.mt.gov/bills/mca/title_0720/chapter_0310/part_0030/section_0530/0720-0310-0030-0530.html

Another section of Montana law deals with the Health Care Power of Attorney. This type of POA requires language that the individual needing support show intent to give medical decision making authority that will still be in place even if/after the principle is incapacitated. For example, the POA might include: "This durable health care power of attorney is not affected by subsequent disability or incapacity of the principal or lapse of time. I _____ hereby designate _____ to act as my durable power of attorney for medical decisions."

Additional language and legal references are available at:

http://leg.mt.gov/bills/mca/title_0720/chapter_0050/part_0050/section_0010/0720-0050-0050-0010.html

Montana did not address the need for an Educational Power of Attorney, but that does not mean these documents have not been written or could not be developed. Currently, there is

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just no uniform language in law to reference. Several states have samples that can be shared with an attorney if an individual chooses to use an Educational POA for support. An example from Wisconsin and the Special Needs Alliance is available in Appendix D (The Education Power of Attorney, 2016). Here are links to a couple of others:

How and Why the Educational Power of Attorney Was Created

http://www.waisman.wisc.edu/cedd/Connections/pdfs/Description_EPOA_and_sample.pdf

Mississippi Bend Area Education Agency

https://www.mbaea.org/media/cms/IEP_English_Power_of_Attorney_for_EDM.PDF

Additional Montana-Specific Resources

Montana State University Extension

Power of Attorney

<http://www.msuextension.org/publications/FamilyFinancialManagement/MT199001HR.pdf>

Montana Department of Public Health and Human Services

Powers of Attorney

<http://www.dphhs.mt.gov/Portals/85/sltc/documents/legaldeveloper/1PowerofAttorney.pdf>

Other Important Items

Accessing Services through Providers

As the new young adult transitions to adult service providers, they may want support in understanding the paperwork and processes required to access services. The supported decision-making model can be used, where the individual has a chance to prepare for and practice the conversation so they can actively participate. The person needing support may also want someone to either attend meetings with them or be able to ask for clarifying information on their behalf. In this scenario, an advocacy tool can be used to designate who will assist the individual, what the advocate has access to, and how they will support the individual. A sample form with language that can be adjusted to reflect the intent of the individual being supported is available in Appendix C. This form could be used with agencies such as Vocational Rehabilitation or Mental Health. If medical information will be accessed, the service provider may require a HIPPA release. Please see the *Medical* section of this toolkit for guidance on how to modify the HIPPA release for supported decision-making.

Notarizing Forms

A Power of Attorney, as established by the state of Montana, has a place for the notarizing of signatures. This component could be added to an advocacy form if those creating it felt the notarization added meaning to the tool for all parties. Finding a notary public to assist does not need to be a barrier. Think about the resources in your community. Oftentimes, your local bank will have a notary and offer this as a service to customers. Another option would be to check with local government offices to see if they have someone available to notarize documents for the public. Who are you connected with? Local businesses, secondary education settings or services such as AAA may have someone who can assist you with a notarized signature.

Respect

Sometimes when we are supporting an individual, whether it be as a professional, friend or family member, we can get caught up in what needs to be done and not allow the individual with a disability the opportunity to lead or grow. Consider who is most actively participating, and then consider how to ensure the individual with a disability has the opportunity to provide information and communicate their thoughts. For insight into this topic, please visit the following link for the video *When Listening Is Complicated: Skills for Honoring the Individual Perspectives of Every Person with Disabilities* by Ruti Regan: <http://www.ucsd.tv/search-details.aspx?showID=32191>

End-of-Life Decisions

While end-of-life conversations can be extremely difficult and painful, they are an important consideration. A resource that may be helpful in guiding these conversations is available at: Coalition of Compassionate Care of California

Thinking Ahead: My Life at the End

<http://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>

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Final Thoughts

Next Steps

After reading through this toolkit, you may have determined that a guardianship is not necessary or the best course of action to support the individual with a disability in decision-making. Hopefully you have identified alternative tools to fit your situation. Once you have chosen which tools to use, decide who needs to have a copy (for example, the family lawyer and an adult sibling who lives outside the home). Be sure to keep a copy for yourself. Make a list of who has copies so that if changes are made, the updated version(s) can easily be shared. You may want to develop a cover letter stating what is being provided and who to contact if there are questions. If the tool is to be for educational purposes, ask that the records and/or IEP meeting minutes show you have provided the tool. For agencies, ask to have the tool added to the supported individual's file.

If you begin this process early, there is time for exploration, learning, and growth to occur. This gives young adults and their family members the opportunity to develop their capacity and become proficient in using a team approach to decision-making, and gives everyone time to adjust to new roles.

Undoing Guardianship

Guardianship is a legal process in which the court determines an individual does not have the capacity to make decisions either generally or in specific areas. What happens if their capacity changes? Perhaps when the guardianship was established, it was considered the best way to support the individual. Maybe with training and time to develop decision-making skills, their abilities have grown. In Montana, the law allows for removing a guardianship of an adult no longer believed to be incapacitated. This is referred to as "termination of incapacity" and is addressed in the Montana Code Annotated 72-5-325 (2017a). A request must first be made to the court, and then the individual under the guardianship or someone who knows them well can request a petition for an order to establish if the individual is no longer incapacitated and for the termination of the guardianship. The same process is used for establishing and terminating a guardianship. Just as documentation was needed to show the individual did not have the capacity to make decisions, now documentation will be needed to show that they have the capacity to do so. The court can then modify or terminate the guardianship.

Additional Resources

American Bar Association

Restoration in Adult Guardianships (statutes)

https://www.americanbar.org/content/dam/aba/administrative/law_aging/2013_CassidyRestorationofRightsChart7-13.authcheckdam.pdf

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General Resources

ASAN, Autistic Self Advocacy Network

The Right to Make Choices: New Resource on Supported Decision-Making

<http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>

The Right to Make Choices: International Laws and Decision-Making by People with Disabilities

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-For-Families-v3.pdf>

The Arc

The Arc's Self-Determination Scale, Adolescent Version

<http://www.thearc.org/document.doc?id=3670>

Center for Parent Information and Resources

Getting Ready for When Your Teen Reaches the Age of Majority: A Parent's Guide

<http://www.parentcenterhub.org/repository/age-of-majority-parentguide/#who>

Getting Ready for Healthcare at the Age of Majority

<http://www.parentcenterhub.org/repository/aom-series-healthcare/>

Getting Ready for Managing Finances at the Age of Majority

<http://www.parentcenterhub.org/repository/aom-series-finance/>

Statewide Parent Advocacy Network, Inc.

Supported Decision Making and Alternatives to Guardianship

<http://www.spanadvocacy.org/content/supported-decision-making-and-alternatives-guardianship>

Office of Developmental Primary Care

What's Next?: A Self Advocate's Guided Tour through Transition for Parents and Other Supporters

http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/FINAL%20Trans%20Guide%2011.18.16%20ALL_0.pdf

Appendices

Appendix A: Consent to Authorize Advocacy and Release of Information

Appendix B: Designation for Patient Advocate for Care, Custody, and Medical Treatment Decisions

Appendix C: Consent to Authorize Advocacy and Release of Information

Appendix D: Special Durable Power of Attorney for Matters Concerning Education

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Appendix A - Sample Language

CONSENT TO AUTHORIZE ADVOCACY AND RELEASE OF INFORMATION

I, (full name), hereby authorize (X) School District to release and exchange information with my advocate, (full name), which pertains to my school program and placement. I am also requesting that my advocate be invited to any and all meetings about me, and I do not want any decisions made without (his/her) input. I do not wish to discuss issues or concerns about my school day or program without my advocate present. If the school or district has any documents I need to sign, my advocate must sign first with me present, before I will sign. This authorization, unless otherwise revoked by me, will remain in effect for the durations of the time I receive special education services and until my twenty-fifth birthday. My advocate read through this paper with me prior to my signing to make sure I understood and wanted this agreement.

(Full Legal Name)

(Date)

Appendix B - Sample Language

DESIGNATION FOR PATIENT ADVOCATE FOR CARE, CUSTODY, AND MEDICAL TREATMENT DECISIONS

I am (full name) and I live at (street address) in (city), (state). I want (full name of advocate), my advocate, to help me if I am sick and if I need to go to the doctor.

My advocate read this paper to me before I signed the paper and I understood what they told me about this paper.

If I am sick, my advocate should take me to the doctor. If (he/she) is not at my house when I become sick, please call (her/him) at (contact #) to go the doctor's office. I would like the doctor to talk to (her/him) about what is the matter with me.

I would like the doctor to ask my advocate what we have decided the doctor should do. I would like the doctor to do what the advocate tells the doctor to do in regards to my treatment.

Sometimes a doctor says that I need to have a shot or some other care. Sometime the doctor says I need to take pills or medicine. My advocate and I will talk about it and decide if I should have the shot, or take a pill, or some other medicine. My advocate will also help me decide what other care I should have, but (she/he) will talk to me about what care I need.

If I am very sick, I might need to go to a hospital. My advocate will help me decide if I need to go to the hospital. I would like all the people at the hospital to speak with my advocate and myself about what the people at the hospital should do for me. I would like my advocate to assist me to decide about my care at the hospital even if I am unable to understand what the doctor says about me. This is very important since I want the people at the hospital to try very hard to care for me if I am sick. If I need to have an operation because I am very sick, I would like to have the people at the hospital talk to my advocate. My advocate will say "yes" or "no" and that is what the people at the hospital are to do.

I would like my advocate to be considered my designated lay caregiver in agreement with Title 50, Chapter 5.

I understand that I want my advocate to help decide what care I need, and I want people to listen to (her/him) about my care.

If my advocate is not happy with my doctor, then (she/he) is able to get another doctor to take care of me.

(Full Legal Name)

(Date)

Appendix C - Sample Language

CONSENT TO AUTHORIZE ADVOCACY AND RELEASE OF INFORMATION

1, _____

authorize (name of agency or organization) to release/exchange information with (my friend/advocate, or could list specific person) which pertains to my (services, programs and living situation). I also wish that (my friend/advocate, same as above) be invited to any and all meetings about me, and I do not want any decisions made without his/her input. If (agency or organization) has any documents I need to sign, (my friend/advocate, same as above) should receive copies and have time to go over them with me before I am asked to sign. This authorization, unless otherwise revoked by me, is intended to remain in effect for the duration of time I receive services, etc., or until I revoke this authorization, whichever comes first.

(Name)

(Date)

Appendix D - Sample Language

SPECIAL DURABLE POWER OF ATTORNEY FOR MATTERS CONCERNING EDUCATION

[The following document is substantially similar to one prepared by Attorney Barbara S. Hughes of Hill, Glowacki, Jaeger & Hughes, LLP, Madison, Wisconsin, with input from school district legal counsel for use in several specific cases for clients in the Madison Metropolitan School District. The original instrument has been accepted by the local vocational/technical school and the University of Wisconsin in at least one case. This document is shared subject to the express understanding that it must be reviewed by legal counsel and adapted as appropriate in other cases.

This document is intended for informational purposes only, and does not constitute legal advice. Barbara S. Hughes and the Hill, Glowacki, Jaeger & Hughes, LLP law firm expressly disclaim all responsibility for all consequences of use of this material.]

I, _____, hereby designate my _____ **relationship** _____, _____ **name** _____, as my Agent to handle the control and management of my education on my behalf.

I designate my _____ **relationship** _____, _____ **name** _____, as my alternate Agent to handle the control and management of my education on my behalf if my Agent is ever unable or unwilling to serve. An alternate Agent shall have the same powers under this instrument as the initial Agent.

My Agent is authorized in my Agent's sole and absolute discretion, with respect to the control and management of my education, to do every act and thing whatsoever necessary, proper or convenient to be done as fully as I might or could do for myself. By the granting of this Special Durable Power of Attorney for Matters Concerning Education, I intend to give my Agent the broadest possible powers to represent my interests in all aspects of any dealings or decisions involving my education.

The following powers are specifically included, but the listing of such specific powers shall not restrict the exercise of the broad and general powers granted:

1. To provide opportunities for me to engage in any public and/or private educational programs.
2. To make decisions for me concerning my education.
3. To provide opportunities for me to engage in any recreational activities having an educational purpose.

4. To investigate and arrange for opportunities for me to engage in educational activities that provide occupational training.
5. To enroll me in any educational programs.
6. To authorize any services for me that are designed to provide me with educational benefit and/or access to a free, appropriate public education in public school as provided for in the Individuals with Disabilities Education Act.
7. To negotiate and approve on my behalf reasonable accommodations in education services as required under Section 504 of the Rehabilitation Act of 1973.
8. To have access to my school records and other personal education information. The scope of this power shall also extend to confidential records and information, whether prepared by school personnel or by third parties, including but not limited to medical services providers, psychological services providers, assistive technology providers, speech, physical and occupational services providers, social work providers, and any provider of durable medical equipment. ***[Attorney Hughes recommends having the client execute an attorney-drafted HIPAA release to facilitate coping with stringent health care records privacy requirements, potentially allowing re-release of health care records to carefully circumscribed recipients, including the client's attorney. This must coordinate with the client's health care power of attorney document, since the health care agent is usually the "personal representative" for HIPAA purposes.]***
9. To attend and participate in all school meetings and conferences pertaining to me.

REVOCATION OF POWER OF ATTORNEY

I may revoke this Special Durable Power of Attorney for Matters Concerning Education by a writing signed and dated by me.

RELEASE OF THIRD PARTIES

In the absence of actual notice that I have revoked this instrument, no person, school district or its personnel, organization, corporation, or other entity who deals with my Agent shall incur any liability to me, my estate, my heirs, or my assigns for permitting or facilitating my Agent in the exercise of the authority granted under this instrument. I hereby release all such persons, organizations, corporations or other entities from any liability arising from their reliance on this instrument.

PHOTOCOPIES

I authorize that photocopies of this instrument may be made, and that these photocopies shall have the same force and effect as the original.

Firm phone

References

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