



Sharon Williams, Past Chairperson

Missouri Developmental Disabilities Council

[www.moddcouncil.org](http://www.moddcouncil.org)



# Proposed Legislative Reform

- Missouri Working Interdisciplinary Network of Guardianship Stakeholders (MO-WINGS)
- MO-WINGS has worked to develop model language to improve law
  - Chapter 475, RSMo
    - Incorporate recommendations of National Guardianship Summits
    - Consider alternatives to guardian/conservator appointment
    - Emphasize person-centered services
- Second, develop policy guidance & best practices
- Third, educate, train, evaluate, address need for further changes



# Guardianship

- It is not uncommon for guardianship to be suggested for individuals who need help with regular activities of daily living, such as managing money, managing medications, or health care decisions. Prior to seeking guardianship, it is **IMPORTANT** to understand the implications of guardianship and the long term effects it has on an individual's life.



# Decision Making

- The right to make decisions plays an important part in defining all of us as human beings.
- We want people to have the level of protection and support they need – no more and no less. Understanding options and alternatives to guardianship helps explore this.



# Options and Alternatives

- There is no single correct answer for all families and/or individuals considering guardianship or options and alternatives for support and protection.
- This a big decision for individuals with intellectual and developmental disabilities and their families. Each situation is different and the options families choose may be different in each individual situation.



# Assessing the need for protection and or support

- The first step is to determine what level of ability the person has with regard to key areas of his/her life.
- “The tool” can be helpful in most accurately determining if there is an option or alternative that meets the individual’s needs for support and/or protection.

IDENTIFYING ALTERNATIVES TO GUARDIANSHIP			
Name of Individual: _____			
Relationship to individual (circle one): Self Family Friend Guardian Other: _____			
How long have you known the individual? _____			
<p>This checklist is a tool designed to be used <i>only</i> for the purposes of the training program.</p> <p><b>NO Guardianship: Understanding Your Options &amp; Alternatives.</b></p> <p>It is designed to assist with identifying a person's ability to make decisions and manage key areas of the individual's life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.</p> <p>The questions listed below are <i>not</i> exhaustive and are <i>not</i> intended to provide a final determination of what a person should (or should not) do in these unique circumstances.</p>	<p><b>LEAST RESTRICTIVE</b></p> <p>Individual Makes Own Decisions</p> <p>"YES" "YES" places a ✓ in the box.</p> <p>If the answer is "NO," go to next column →</p>	<p><b>MOST RESTRICTIVE</b></p> <p>Individual Needs Support With Major Decisions</p> <p>"NO" If there is an ALTERNATIVE that meets this need, but it better meet this need, go to next column →</p> <p>If NO Alternative meets this need, go to next column →</p>	<p><b>MOST RESTRICTIVE</b></p> <p>Individual has NO RIGHT to Make Decisions</p> <p>"NO" Place a ✓ in the box and indicate whether you need additional help with one of the GUARDIANSHIP OPTIONS</p>
	<p>→ → → →</p>		
<b>EMPLOYMENT</b>			
Can the person make and communicate choices in regard to employment?			
Can the person look for and find a job (or re-employment agency, <i>retired or not, see answer?</i> )			
<b>MONEY MANAGEMENT</b>			
Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?			
Is the person able to manage the monetary benefits he or she is supposed to receive?			
Is the person able to identify and enroll financial professionals?			
<b>HEALTH &amp; NUTRITION</b>			
Does the person make decisions about where, when, & what to eat?			
Can the person follow a prescribed diet and/or take medications as directed?			
Does the person understand the need to maintain personal hygiene and dental care?			
Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?			
Does the person understand health consequences associated with high risk behaviors ( <i>substance abuse, smoking, high-risk sexual activities, etc.</i> )			
Can the person seek others and seek medical help for serious health problems?			



## Options and Alternatives to Guardianship

- Supported Decision-Making
- Power of Attorney
- Durable Power of Attorney for Health Care
- Living Will
- Limited and/or Joint Bank Accounts
- Direct Deposit and Automatic Bill Pay
- Temporary Restraining/Protection Orders



## Supported Decision-Making

Supported Decision-Making is a recognized alternative to guardianship through which people with disabilities use friends, family members and professionals to help them understand the situations and choices they face, so they may make their own decisions without the need for a guardian.





## Supported Decision-Making

- There is no “one size fits all” method of Supported Decision-Making.
- Can include, as appropriate:
  - Informal Support
  - Written agreements identifying the support needed and who will give it.



## Supported Decision-Making

- Supported Decision-Making can help people:
  - Understand information, issues, and choices
  - Focus attention in decision-making
  - Weigh options
  - Ensure that decisions are based on their own preferences
  - Interpret and/or communicate decisions to other parties



## Individuals and Families Share Experiences

- Caroline's story
- When Caroline was 18 her mother got a limited guardianship. At 20, she was kicked out of the house and her nightmare began. A court hearing was held where mom relinquished the limited guardianship. A public administrator was appointed and Caroline was labeled as "totally incapacitated and a danger to herself." At this time she had graduated from high school, gotten her driver's permit and been working for 4 years. She was placed in a very restrictive living environment. With assistance from advocates and an Attorney to represent Caroline she eventually gained partial restoration of her rights. Caroline has completed 3 college courses, works full-time, and now has her own apartment. She is extremely happy and doing well.



## Individuals and Families Share Experiences

- Cristal's story
- Cristal lives with her husband in the community. She enjoys knitting, and taking care of her pets. She also likes to work with groups in her community. For four years, Cristal was barred from much of what she is grateful for today because of restrictions placed on her by guardianship. "If you have a guardian, it's like you don't have a voice," she said. She was diagnosed with bi-polar in her youth. She was looking for help during a stressful time and was deceived by someone she trusted. She was placed under the guardianship of a public administrator, who then moved her to a residential care facility.



## Individuals and Families Share Experiences

- Cristal's story continued
- The facility Cristal resided in was closed after it failed a series of government reviews. Guardianship was eventually transferred to a family member. She was trying to have her rights restored when this family member passed away. A court arranged a hearing to review her guardianship arrangement. Determined to restore her rights she found information and submitted her application for services with Missouri Protection and Advocacy. Mo P&A assisted Cristal and her rights were restored. She wants people to understand how guardianship can be restrictive and to share information about alternatives to guardianship.



## Individuals and Families Share Experiences

- Ashley's story
- Soon, Ashley would be turning 18. Her mother wanted to handle her transition to adulthood in a way that would avoid the potential limitations guardianship presented. "I worked all of her life to let her become her own person." I didn't want to take anything away from her. Wondering what she could do to avoid guardianship yet still provide her daughter with the supports she needed to pursue her dreams she learned about Mo P&A. Understanding that guardianship involved a legal declaration that Ashley was incapacitated and unable to make decisions for herself and was something that is more difficult to overturn than to obtain, they began exploring options that would allow her to pursue the goals she set for herself. Legal documents were drafted that would provide her with the supports she desired after her eighteenth birthday. They established a Power of Attorney for Health Care and a General Power of Attorney for Finances, Education and Housing. Ashley understood the new arrangements meant that she would continue to have support from her mother without guardianship's restrictions.



# Introduction of Publications

[www.moddcouncil.org](http://www.moddcouncil.org)



## MO Guardianship: Understanding Your Options & Alternatives

### A RESOURCE GUIDE

*helping you understand how to:*

- **BALANCE SUPPORT & PROTECTION** with autonomy and self-determination.
- **IDENTIFY OPTIONS AND ALTERNATIVES**
- **ACCESS ALTERNATIVES TO GUARDIANSHIP** as well as accessing Missouri courts to pursue your guardianship options.

December 2010



**Institute for Human Development**

A University Center for Excellence in Developmental Disabilities  
715 W. Franklin, 5<sup>th</sup> Floor • Kansas City, MO 64108  
816.235.1770 • www.kumc.edu



# Introduction of Publications



Missouri Developmental Disabilities Council  
 1706 E. 52nd Street, Jefferson City, Missouri 65102  
 573-751-4661/500-840-7676/573-526-2755 (FAX)  
 Marcia Williams, Chairperson Kelly Goshorn, Executive Director

[www.moddc.org](http://www.moddc.org)  
 811 E. Graham, Des Moines

### Self-Determination and Guardianship

**The Missouri Developmental Disabilities Council's Position:**  
 Because everyone has the right to direct their own lives to the maximum of their ability, people should not be ordered or kept under guardianship just because they have a disability, need (or want) support, or live (or want to live) in a particular place. People should only be ordered or kept under guardianship when less restrictive alternatives have failed to help them direct their own lives. Guardianship, when absolutely necessary, should restrict the ward's rights to the minimum extent possible.

**The Missouri Developmental Disabilities Council's Reasons:**  
 Study after study has found that when people with disabilities have more control over their lives – when they have more self-determination – they have better lives: they are more likely to be employed, independent, and satisfied.<sup>1</sup>

Guardianship decreases self-determination because it gives the guardian power to make decisions in place of the ward.<sup>2</sup> People under overbroad or undue guardianship – guardianships that are unnecessary or more restrictive than necessary<sup>3</sup> – can suffer negative life outcomes including decreased health and ability to function.<sup>4</sup> Research has shown that the vast majority of guardianships – over 90%, in one study – authorize the guardian to control all facets of the ward's life.<sup>5</sup> A Congressional subcommittee found the typical ward has fewer rights than the typical convicted felon.<sup>6</sup>

Today, there are more ways to make more people more independent than ever before. Nevertheless, even though a recent study found that people with disabilities who did not have guardians were more likely to be employed, live independently, have friends, and practice the religion of their choice than those with guardians,<sup>7</sup> the number of people under guardianship has tripled since 1995.<sup>8</sup>

Many people with disabilities can manage their own lives without any intervention. For others, there are effective alternatives to guardianship, including Powers of Attorney, Advanced Directives, Representative Payees, ABLE Accounts, Special Needs Trusts, and Supported Decision-Making, that can provide the help they need and want to manage their own lives. For example, when people use Supported Decision-Making, they work with trusted friends, family members, and professionals to help them understand the situations and choices they face, so they can make their own decisions without the need for a guardian.<sup>9</sup> The National Guardianship Association – an organization made up by and for guardians – has stated that such alternatives should be attempted before ordering guardianship.<sup>10</sup>

- The Missouri Developmental Disabilities Council's Recommendations:**
- As a state and society, we must acknowledge that disability does not equal incapability and respect everyone's right to direct their own lives to the maximum of their abilities.
  - Educational and training material about alternatives to guardianship available through Missouri and national organizations, should be provided to people with disabilities and families as well as educational, medical, financial, legal, and other professionals in order to ensure consistency and opportunity across the state.
  - Legislation, such as the recently introduced HB226,<sup>11</sup> should ensure that alternatives to guardianship are fully considered before people are ordered or kept under guardianship.
  - Legislation and/or best practice should ensure that guardianship proceedings are considered throughout Missouri, protect the rights of people being guardianship petitioners – including their right to be represented by an independent attorney – and provide that guardianships, when absolutely necessary, only restrict rights to the minimum extent possible.
  - Missouri should consult with other states, including Texas and Delaware, that have enacted legislation allowing for the preference of self-determination and the use of alternatives to guardianship.

1. Self-Directed Support Study: People who use self-directed support are more independent and satisfied than those who do not.



## Introduction to Supported Decision-Making







Thank you!

