

Rethinking Guardianship/Supported Decision-Making

Dohn Hoyle
The Arc Michigan



RETHINKING GUARDIANSHIP/ Supported Decision-Making

DOHN HOYLE

1325 S. Washington Ave
Lansing, MI. 48910
(517) 487-5426
www.arcmi.org



The following is an adaptation of the “Statement of Principles” by the Coalition on Alternatives to Guardianship”.

STATEMENT OF PRINCIPLES

SUMMARY STATEMENT

Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express those choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of her/his right to be accommodated and supported in choosing and making decisions and which appoints a substitute decision-maker based on tests of competence, makes that person vulnerable and deprives him/her not only of his/her right to self-determination but also of other rights which should be inalienable.

PRINCIPLES

1. Each individual can choose and make decisions about his/her life
2. Each individual has the right to make decisions (self-determination)
3. Individuals may want help from other persons of their choosing with whom they have trusting relationships, including family members or friends, to make decisions or have them interpreted, and to communicate them to others. This is called supported decision making.
4. Individuals who have an intellectual disability may communicate choices, wishes, likes and dislikes in non-traditional ways which can include actions rather than language. Friends, family members, or others who are trusted by the individual, can help to interpret these decisions.
5. This natural interdependence of people must be recognized and supported decisions that are made within such trusted, supportive relationships must be given status and validation.
6. All adults have the right to make decisions with support or to name a substitute (e.g. by power of attorney) to make decisions for them.

Principles, Continued...

7. Laws and/or policies that do not recognize supported decision making or that protect other interests at the expense of the individual's right to self-determination discriminate against persons who have an intellectual disability and make them more vulnerable
8. Individuals should never be assessed to determine competency; decisions should be reviewable if there is concern that the will of the individual is not being respected or that the individual is being exploited.
9. Any legal system or proceeding which sets up a test of competency to be used to appoint a substitute decision-maker puts the individual at risk of also losing other rights.
10. A decision that could not have been made by the individual without support, e.g. consent for non-therapeutic sterilization, experimentation or other non-therapeutic procedures which could offend human dignity, should not be made within supported decision making relationships.

TASH RESOLUTION

“Be it resolved that TASH, an international advocacy association of people with disabilities, their family members and other advocates, and people who work in the disability field affirms the rights of persons with disabilities and commits to the promotion and use of alternatives to guardianship rather than the removal of said rights. TASH urges the development and promotion of the use of accommodations and supports people need to make choices and decisions, to have their preferences recognized and honored, and to have their rights to self-determination protected.”

Today

- **Guardianship**
 - What it is and what it isn't
 - What it does do and what it doesn't do
- **Ways to address barriers**
- **Tools that help**

Guardianship is a situation,
recognized by law, under
which one person or entity
exercises power over and on
behalf of another person.
("the Ward")

Michigan has Two Statutes Dealing with Guardianships

- Chapter 6 of Michigan's Mental Health Code
 - Persons with Developmental Disabilities
- Michigan Estate and Protected Individual Code
 - All Others

“We have to reject the very idea of incompetence. We need to replace it with the idea of ‘assisted competence’. This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision-making that will preserve their rights...”

-Thomas Nerney, Director of Center for Self Determination
for Persons with Developmental Disabilities

“The typical ward has fewer rights than the typical convicted felon – they no longer receive money or pay their bills. They cannot marry – or divorce... it is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception of...the death penalty”

-Claude Pepper, U.S. Representative

Connecticut Supreme Court

“Guardians appointed by the court whether limited or plenary, can be vested with substantial powers over a respondent. Therefore...the appointment of a guardian implicates a respondent’s constitutional rights...”

(Oller vs. Oller-Chiang, 1994)

Iowa Supreme Court

Guardianship “...involves significant loss of liberty similarly to that present in an involuntary civil commitment for treatment of mental illness.”

(In Re: Hedin, quoting Arizona Court of Appeals)

California Supreme Court

“[A person who has] a conservator [appointed] may be subject to greater control of his or her life than one convicted of a crime”

“...We need to explore alternatives to guardianship such as supported decision-making that enable people to avoid this civil death.”

Phoebe Ball
Legislative Affairs Specialist
National Council on Disability

National Core Indicators (2017)

Adults with developmental disabilities served:

- **Nationally** 53% have a guardian
- **Michigan** 76% have a guardian

The United Nations Convention on the Rights of Persons with Disabilities

In the Preamble:

Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices

Defines discrimination, in part as:

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, of all human rights and fundamental freedoms”

Article 3

General Principles

The principles of the present Convention shall be:

- A) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
- C) Full and effective participation and inclusion in society

Article 5

Equality and Non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

Article 12

Equal recognition before the law

- 1) States Parties affirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- 2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12 (*cont'd*)

3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

The vast majority of those who end up petitioning the court to appoint a guardian for some person are either related to the person or a friend

However, most petitioners do not come to the decision to seek guardianship on their own, but are encouraged to do so by someone else

Iowa Supreme Court

“In making a determination as to whether a guardianship should be established...the court must consider the availability of third party assistance to meet a ...proposed ward’s need for such necessities...”

(in the Matter of Hedin, 1995)

Utah Supreme Court

(re: “Responsible Decisions”)

“...responsible focuses the appointing authority’s attention on the *content* of the decision rather than on the ability of the individual to engage in a rational decision making *process*.”

(In re: Boyer)

Pennsylvania Supreme Court

“Persons cannot be deemed incapacitated if their impairments are counterbalanced by friends, family or other support.”

In re: Perry, 727 A2d 539 (Ps. Sup. Ct. 1999)

CMS: Centers for Medicare and Medicaid Services

Quality Framework Includes:

- PERSON-CENTERED SERVICE PLANNING AND DELIVERY:
 - . . .responses to changing needs/choices and participant directions
- RIGHTS AND RESPONSIBILITIES
 - Protection of rights and decision-making authority. . .

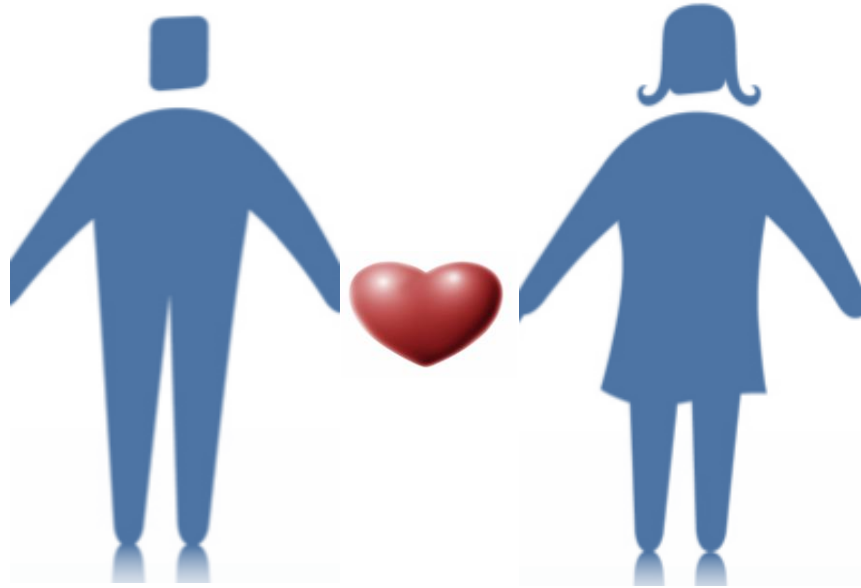
www.cms.hhs.gov/HCBS/downloads/qualityframework.pdf

Values

- Person-Centered
- Self-Determined
- Community-Based
- Recovery-Oriented
- Evidence-Based
- Culturally Competent

**Undoing or Reversing Guardianship is
known as:**

Restoration of Rights



Intentions of Families when they become Guardians:

- Support their children
- Guide their children



REALITY OF INVITING GOVERNMENT INTO YOUR RELATIONSHIP WITH YOUR CHILD:

- The government is much larger than your family and will be personally involved in your family business
- You and your family will be accountable to the government
- The government can decide to remove you from the relationship

PAST REASONS FOR SEEKING GUARDIANSHIP?

- Medical reasons
- Contracts
- Decisions about programs, records, etc.
- Administrative convenience
- Financial decisions
- Placement decisions
- Sex and related issues
- What will happen when parents or family are no longer around?

Dear Mr. Hoyle:

“The American Bar Association (ABA) Commission on Disability Rights – with the ABA Commission on Law and Aging and in partnership with the Administration on Intellectual and Developmental Disabilities (AIDD) within the Administration for Community Living in the U.S. Department of Health and Human Services – Invites you to participate in a pioneering consensus Roundtable discussion, *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities.*”

“The aim of the Roundtable is to empower and support the decision-making of the growing population of individuals with intellectual disabilities, moving beyond the current guardianship model. Specifically, participants will examine problems with the current system of decision-making, propose possible solutions, and recommend initial steps for getting there. The Roundtable is intended to advance a national symposium that will be framed by the recommendation from the Roundtable.”

Dear Dohn,

“I am pleased to invite you to participate in a groundbreaking effort to envision and ensure the future of Supported Decision-Making: a critical and cutting-edge issue for people with disabilities, seniors and others who need or want assistance making life choices and an alternative to overbroad or undue guardianship.

On October 24, 2013, Quality Trust for Individuals with Disabilities, the Council on Quality Leadership and the Burton Blatt Institute are sponsoring a one-day invitational symposium on Best Practices in Supported Decision-Making. Hosted by American University College of Law in Washington, DC, the symposium will develop specific recommendations for advancing the legal, policy, research and practical aspects of Supported Decision-Making.”

Dear Dohn,

“I am pleased to invite you to participate in the Supported Decision-Making (SDM) Symposium 2015 sponsored by the National Resource Center on Supported Decision Making (NRC-SDM). NRC-SDM is a national effort to advance the use of supported decision-making in practice for people needing assistance making life decisions.”

“...On November 18 and 19th, 2015 we have planned a one and a half day symposium agenda to highlight efforts underway to advance the use of SDM throughout the country. This is an invitational symposium to include leaders with expertise in supports for people who are aging and living with a disability. Hosted by American University Washington College of Law in Washington, DC, the symposium will result in discussions on the legal, policy, research and practical aspects of implementing Supported Decision-Making. We will also be identifying next steps and new partnerships needing for future progress.”

Symposium “Vision:

Expand and advance the use of SDM by creating a new paradigm focused on ensuring that older adults and people with disabilities have a TRUE opportunity to (1) be and remain equal members of their communities throughout the lifespan (2) actively use practices and supports that preserve and advance their personal vision for life; and (3) achieve positive life outcomes (e.g., integrated employment, full inclusion, access to health care, individual flourishing, etc.) that reflect personal desires, choices and preferences.”

Tina M. Campanella, CEO, Quality Trust for Individuals with Disabilities

Dear Dohn Hoyle,

On behalf of the Autistic Self Advocacy Network (ASAN), we would like to invite you to join us for a two-day summit on supported decision-making on October 18th and 19th. The summit will be in DC and will be in partnership with the Open Society Foundation.

Our goal is to bring together self-advocates, attorneys, doctors, family members, and advocates to discuss how supported decision-making helps people with disabilities move out of institutions and into the community. The summit's participants will be national and international, bringing a wide variety of perspectives on decision-making and disability rights. The summit would entail participation in multiple group discussions on SDM and deinstitutionalization. There may be several panels at the summit. We think that your advocacy and supported decision-making expertise would contribute a great deal to the practical discussions on SDM laws and their implementation.

You are a long-standing advocate for effective supported decision-making and freedom from restrictive institutions such as guardianship. We would be honored to have you at the symposium.

Please let us know if you can attend.

Sincerely,

Kelly Israel and Samantha Crane
ASAN Legal and Public Policy Team

Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express their preferences/choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of his/her right to be accommodated and supported in choosing and making decisions and which appoints a substitute decision-maker based on test of competence or capacity, makes that person vulnerable and deprives him/her not only of his/her right to self determination but also of other rights which should be inalienable. Our obligation is to find the best ways to provide the accommodations, and supports a person needs to maintain their autonomy and make decisions.

**We can no longer ignore
the great incongruity of
removing a persons rights
to protect them.**

Supported Decision-Making

- Advisors, Advocates
- Person-Centered Planning
- Power of Attorney
- Durable Power of Attorney
- Durable Power of Attorney for Health Care or Designation of Patient Advocate
- Protective Orders
- Trusts
- Contracts – Void vs. Voidable
- Finances – Numerous Options

Person Centered Planning

“Person-centered planning’ means a process for planning and supporting the individual receiving services that builds upon the individual’s capacity to engage in activities that promote community life and that honors the individual’s preferences, choices and abilities. The person-centered planning process involves families, friends, and professionals as the individual desires or requires” MCL 330.1700 (g)

Michigan’s Long Term Care Group Report and Recommendation,
June 2000

PERSON CENTERED PLANNING

A person centered plan assists individuals to create a personalized image of a desirable future. The development of a plan suggests a process that can organize and guide community change in alliance with people with disabilities thus building the bridge from both sides.

Essential to all person centered plans are the following characteristics:

Person Directed – The plan for the person is that the person’s vision of what he or she would like to be and do. The plan is not static, but rather it changes as new opportunities and obstacles arise.

Capacity Building – Planning focuses on the person’s gifts, talents and skills rather than deficits. It builds upon the individual’s desire to engage in activities that promote a sense of belonging in the community.

Person Centered – The focus is continually on the person for whom the plan is being developed, and not on plugging the person into available slots in a program. The individual’s choices and preference must be honored.

Network Building – The process brings together people who care about the person, and are committed to helping the person articulate their vision of a desirable future. They learn together and invent new courses of action to make the vision an reality.

Outcome based – The plan focuses on increasing any or all of the following experiences which are valued by the individual:

- Growing in relationships or having friends.
- Contributing or performing functional/meaningful activities.
- Sharing ordinary places or being part of their own community.
- Gaining respect or having a valued role which expresses their gifts and talents.
- Making choices that are meaningful and express individual identity.

Community Accountability – The plan will assure adequate supports when there are issues of health and safety, while respecting and according them full dignity as a fully participating member of the community.

Person Centered Planning

- Preferences determined by person centered planning process are honored unless harmful to the individual
- This process of determining preferences and choices enhances the dignity and self-determination of individuals
- This process is more reliable than having a court-appointed person to make decisions with or without input from anyone.

Michigan Social Welfare Act

MCL 400.66h

- ❖ Affirms a person's right to provide consent to treatment and have wishes followed when receiving government assistance (i.e., Medicaid).
- ❖ If the individual is unable to make medical decisions, then providers are required to obtain written consent of individual's nearest relative, guardian or parent except in emergencies.

Medical Power of Attorney

- Appoint an Agent to handle medical decisions or support you in medical decisions
- Can be effective immediately
- Can be as broad or narrow as desired

POWER OF ATTORNEY FOR MEDICAL TREATMENT DECISIONS

I am _____ and I live at _____.
I want my mother, _____ to help me if I am sick and need to see a doctor. I want her to make decisions about my medical care, including medication and surgery.

If my mother, _____ is not available, I would like my _____, _____ to make these decisions instead.

If neither of the above are available, I would like my _____, _____ to make these decisions.

I understand that if I want to change my mind about who makes these decisions, I can destroy this paper or let people know I want to change my mind.

(Date)

(Signed)

Signed by _____ Signed by _____

(Print full name)

(Print full name)

POWER OF ATTORNEY FOR MEDICAL TREATMENT AND SUPPORT DECISIONS

I am _____. I live at _____, _____, MI _____. I want my Mother, _____, to help me if I am sick and if I need to go to the doctor.

If I am sick, my Mother should take me to the doctor, I would like the doctor to talk to her and tell her about my illness and if I need medicine or other treatments. After talking to the doctor, I want my Mother to decide what care I should have. I want my Mother to be able to look at and have copies of all my medical and hospital records. Please share these records with her and give her copies if she asks for them.

I would also like my Mother to decide if I need to go to the dentist.

If I am very sick, I might need to go to a hospital. My Mother can decide if I need to go to the hospital. I would like all of the people at the hospital to speak with my Mother about what the people at the hospital should do for me. After talking to the doctor, I want my Mother to decide what care I should have.

I understand that I want my Mother to decide what care I need, and I want people to listen to her about my care. If my Mother is not happy with my doctor or any other care provider, then she is able to get another doctor or provider to care for me.

I would like my Mother to assist me with getting services and supports from the community mental health agency and any and all other social service agencies. My Mother should read all the documents from these places and talk to me about them. If my Mother agrees, I will sign the documents, but I want my Mother to sign them too.

If my Mother is, at any time, unable or unwilling to act, I then appoint my Father, _____ as my agent. If my Father is, at any time, unable or unwilling to act, I then appoint my Brother, _____, as my agent.

I understand that if I want to change my mind about who makes these decisions, I can destroy this paper or let people know I want to change my mind.

Dated:

Signed by _____ Signed by _____

(Print full name)

(Print full name)

Finances

- Representative Payee
- Limited Bank Account
- Automatic Bill Paying
- Personal Money Managers

Representative Payee

- A person or organization designated through the Social Security Administration to handle a person's Social Security check
- SSA has special paperwork and procedures for appointing a representative payee
- Can be changed or revoked only if SSA consents

Limited Bank Accounts

- Co-Signers
- Ceiling Limit Account
- Pour-Over Account

Automatic Bill Paying

- Automatic bill payment can be set up for an individual
- Eliminates the ongoing need for bill payment assistance
- Periodic monitoring is helpful

Personal Money Manager

Personal Money Managers are individuals or organizations that can handle finances for an individuals. Services include:

- Paying bills
- Managing finances
- Handling Investments
- Troubleshooting

Estate Planning for People with Disabilities

Estate Planning for people with disabilities is generally done to preserve eligibility for governmental benefits that provide essential services.

Trusts

- Settlor/Grantor
 - Creates the Trust
- Trustee
 - Manages the Trust
- Beneficiary
 - Receives the beneficial use of the trust

Types of Trusts for People with Disabilities

- Support Trust
- Medicaid Qualifying Trusts:
 - Amenities Trust/Special Needs Trust
 - Payback Trust
 - Pooled Trust

Trust can be used for:

- Medical treatment beyond Medicaid
- Dental Care
- Educational or Vocational services
- Recreation expenses or outings
- Travel for beneficiary or siblings, etc.
- Books, magazines, cable television, phone calls
- Monitoring expenses
- Non-standard or non-covered personal services
- Can purchase home & rent to beneficiary with or without roommates (payments must cover total cost of home)
- Can make the difference between success & failure of a placement
- Favors consumer choice & inclusion

Self-Determination Principles

- **Freedom:** The ability to plan a life, rather than purchase a program
- **Authority:** Ability for a person with a disability to control a certain sum of dollars to purchase supports
- **Support:** Arranging resources and personnel, both formal & informal, to achieve meaningful participation
- **Responsibility:** Acceptance of a valued community role, through employment, affiliations, spiritual development and caring for others, as well as accountability for public dollars

Self-Determination

Freedom

- ❖ *Liberty*
- ❖ *Independence*
- ❖ *Autonomy*
- ❖ *Sovereignty*

Guardianship

- ❖ *Lack of Control*
- ❖ *Disparagement*
- ❖ *Loss of Autonomy*
- ❖ *Loss of Rights*

Self-Determination

Authority

- ❖ *Control*
- ❖ *Mastery*
- ❖ *Power*
- ❖ *Rights*

Guardianship

- ❖ *Lack of Authority*
- ❖ *Disparagement*
- ❖ *Subservient*
- ❖ *Loss of Rights*

Self-Determination

Support

- ❖ *Livelihood*
- ❖ *Independence*
- ❖ *Accessibility*
- ❖ *Confidence*

Guardianship

- ❖ *Dependence*
- ❖ *Lack of Freedom*
- ❖ *More exclusion from community*
- ❖ *Low Self-esteem*

Self-Determination

Responsibility

- ❖ *Accountable*
- ❖ *Committed*
- ❖ *Empowered*
- ❖ *Decisive*

Guardianship

- ❖ *Lack of Control*
- ❖ *Disparagement*
- ❖ *No Power*
- ❖ *Loss of Rights*

“ A person’s impairment does not diminish the right of that person to exert choice and control about his or her life or to fully participate in the economic, political, social cultural, and educational mainstream of society.”

Arlene Kanter

QUALITY OF LIFE

People in your life

- Unpaid and paid
- Of your choosing
- Variety and array of relationships

QUALITY OF LIFE

Control

- **Where and how you live**
- **What you do and where you do it**
- **What supports, how, and by whom they are provided**

QUALITY OF LIFE

Money

- **Direct your budget**
- **Opportunity to earn money**
- **Decide how to spend your money**

IT IS....

SELF-DETERMINATION,
NOT
GUARDIAN DETERMINATION

Dohn Hoyle

dhoyle@arcmi.org

1-800-292-7851



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1-800-552-4821

info@michiganallianceforfamilies.org

