

RETHINKING GUARDIANSHIP

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IF WE ARE ABOUT

- EQUAL
OPPORTUNITY

- INCLUSION

- EQUITY

- CHOICE

IF WE SEEK
SOCIAL JUSTICE
AND
THIS IS A
CIVIL RIGHTS
STRUGGLE
Then

HOW CAN WE
COURTENANCE
AND EVEN BE
COMPLICITE
IN THE SYSTEMATIC
GOVERNMENTALLY
SANCTIONED
STRIPPING OF
INDIVIDUAL RIGHTS
THROUGH
GUARDIANSHIP

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.

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.
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.

*Coalition on Alternatives to Guardianship
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People First of Ontario
People First of Canada
Ontario Association for Community Living
Canadian Association for Community Living
Youth Involvement Ontario

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.”

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/family are no longer around?**

WHY AVOID GUARDIANSHIP?

- Avoid public declaration of incompetency
- Promote independence, dignity, freedom of choice
- People deal with guardian – not person
- Expense – attorneys, hearings, evaluations
- Courts don't always follow law (partial vs. plenary, promote independence, etc.)

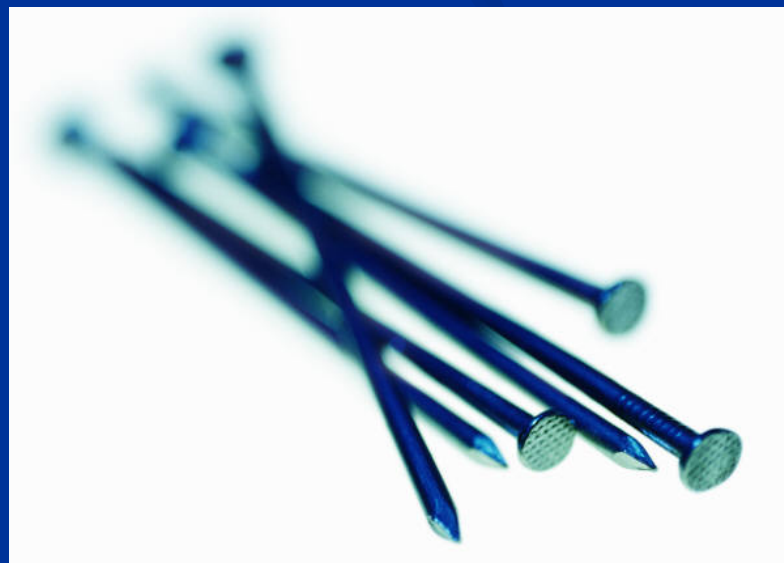
WHY AVOID GUARDIANSHIP? (cont'd)

- Very difficult to modify or terminate
- Attorneys and G.A.L.s – very little training
- Corporate guardian problems – take money & independence
- It simply doesn't do what you want it to do!

When the only tool you have is a
HAMMER



Every problem looks like a
NAIL



Hoyle

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...”

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”

NATIONAL ELDER ABUSE AND GUARDIANSHIP VICTIMS TASK FORCE

*“Too often the very Adult
Guardianship and
Conservatorship System meant
to protect the elderly are being
used as instruments to violate
their rights, rob them of their
lifelong savings and tear them
away from their families and
loved ones.”*

“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

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)

“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 Self
Determination for Persons with
Developmental Disabilities

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

ALTERNATIVES

- **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**

ALTERNATIVES (CONT'D)

- Trusts
- Contracts – Void vs. Voidable
- Finances
 - Representative Payee
 - Limited Bank Account
 - Co-signers
 - Ceiling Limit Account
 - Pour-over Account

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 at 21

Person Centered Planning IS:

- Honoring a person's behavior as communication
- Choice over many aspects of their life
- Control over what each day includes and doesn't include
- Freedom
- Assisting an individual to determine what make
- their life worth living

Cornerstones of PCP

- Presuming competence
- Reframing behavior as communication
- Respecting cultural diversity
- Providing critical supports for health and safety across the lifespan so people may live where and with whom they want

For Non-Traditional Communicators

- All behavior is communication.
- Anything you can see, hear, touch or count is a behavior.
- A person's behavior tells us what they think about other people, and their living and working environments.
- Reframing behavior as communication is the first step in understanding the person who does not communicate in a traditional manner.

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 be organized 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 individuals 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 a 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 their full dignity as a fully participating member of the community.

- 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.

CONSENT TO AUTHORIZE ADVOCACY AND RELEASE
OF INFORMATION

I, _____ hereby authorize
Community Mental Health to release/ exchange
information with my parents, _____
_____, which pertains to my
services, programs and living situation. I also
wish that my parents be invited to any and all
meetings about me, and I do not want any
decisions made without their input. If CMH has
any documents I need to sign, my parents must
sign first to acknowledge their receipt of these
documents and their concurrence with them,
before I will sign. This authorization, unless
otherwise revoked by me, is intended to remain
in effect for the duration of time I receive
mental health services, etc. or until I revoke this
authorization, whichever comes first.

(name)

(date)

CONSENT TO AUTHORIZE ADVOCACY AND RELEASE
OF INFORMATION

I, _____, hereby
authorize _____ Schools
to release / exchange information with my
parents, _____
_____, which
pertains to my school program and placement.
I also wish that y parents be invited to any and
all meetings about me, and I do not want any
decisions made without their input. If the
schools have any documents I need to sign, my
parents must sign first, before I will sign. This
authorization, unless otherwise revoked by
me, is intended to remain in effect for the
duration of time I receive special education
services or until my twenty-seventh birthday,
whichever comes first.

(name)

(date)

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

Patient Advocate Designations (PADs) for Medical Decisions

- Exercisable only in event the person is unable to make their own medical decisions (certified by two physicians)
- Can be individual 18 or over to exercise powers related to care, custody and medical treatment decisions of the person.
- Includes the individual's preferences regarding care and treatment.
- Necessary for withdrawal of life-sustaining treatment.
- New Michigan law also permits PADs for mental health decisions. This is also a preferred alternative to “Kevin’s Law” (court-ordered, outpatient treatment).

(Sample only – revise language or content to reflect the understanding and circumstances of the person signing.)

POWER OF ATTORNEY FOR MEDICAL TREATMENT DECISIONS

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

My mother/father read this paper to me before I signed it. I understand what he/she told me about this paper before I signed it.

If I am sick, my mother/father should take me to the doctor. If she/he is not at my house when I become sick, please call her/him to come to the doctor’s office. I would like the doctor to talk to her/him and tell her/him what the matter is.

I would like to ask my mother/father what the doctor should do. I would like the doctor to do what my mother/father tells the doctor to do; she/he knows what is best for me.

Sometimes a doctor says that I need to have a shot or some other care. Sometimes a doctor says that I need to take pills or medicine. My mother father will also decide what other care I should have, but she/he will talk to me about what care I need.

I would also like my mother/father 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/father 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/father about what the people at the hospital should do for me. I would like my mother/father to decide about my care at the hospital even if I am unable to understand what my 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 the people at the hospital talk to my mother/father. My mother/father will say “yes” or “no” and that is what the people at the hospital will do.

I understand that I want my mother/father to help decide what care I need, and I want people to listen to him or her about my care. If my mother/father is not happy with my doctor, then he or she is able to get another doctor to care for me.

(Signature or Mark)

(Date)

(Witness)

(Date)

(Witness)

(Date)

DESIGNATION FOR DURABLE POWER OF ATTORNEY FOR MEDICAL TREATMENT, RESIDENTIAL PLACEMENT, AND PROGRAM 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.

I also want my mother, _____ to make decisions about where I will live. She can sign any papers needed to arrange for a place for me to live.

I also want her to make decisions about work and other programs that I participate in.

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 would like these powers to last even if I become unable to understand this form in the future. 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)

STATEMENT OF WITNESSES

We sign below as witnesses. This was signed in our presence. The signer appears to be of sound mind, and to be making this designation voluntarily, without duress, fraud or undue influence.

Signed by witness: _____

(Print full name)

Signed by witness: _____

(Print full name)

Representative Payee

- A representative payee is 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

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

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

CREDIT CARDS

TWO METHODS TO OPT-OUT FOR CREDIT CARD OFFERS

- Five Year Opt – Out

Complete form online (secure website)

at: www.optoutprescreen.com

- Permanent Opt – Out

Form must be printed, signed and mailed. (five year opt-out may be completed in the interim)

Call: 1 (888) 567-8688

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

- Grantor (owner of property) transfers property to a Trust, which could include real estate, bank accounts, stocks and bonds.
- The Trust assets are administered by a Trustee.
- The Trustee must manage the assets and make expenditures for the designated Trust Beneficiary in accordance with the trust document.

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
- Amenities Trust
- Payback Trust
- Pooled Trust

Fiduciary Duty

- A Fiduciary is someone who has undertaken a relationship of trust and confidence to act on behalf of another person.
- The Fiduciary duty is the highest standard of care in law or equity.
- A Fiduciary must put the person's interest before his or her personal interest.

Support Trust

- Provides for support, care and maintenance of the beneficiary
- Can be created and funded by anyone including beneficiary
- Does not preserve eligibility for government benefits (e.g., Medicaid, SSI)
- Typically established by family members for individuals with special needs who do not need government benefits

Third-Party (Amenities) Trust

- Established and funded with assets of a third party (e.g. family member)
- Provides for amenities or extra items or services only (e.g., advocacy, recreational activities, home furnishings, haircuts, music therapy)
- If properly written, preserves beneficiary's eligibility for government benefits

Benefits of Amenities Trusts

- Preserves Eligibility for Government Benefits
- Provides for an enhanced quality of life for the beneficiary
- Provides for Trustee to Act as an Advocate

Pooled Accounts Trust

- Used to preserve government benefits
- Established and administered by a non-profit organization.
- Sub-accounts are established for the benefit of the individual.
- Remaining assets at death are left with the non-profit organization.

Pay Back (Self-Settled) Trusts

- Established by a family member or designated individual with trust powers
- Funded with the Beneficiary's own funds (e.g., funds awarded from lawsuit)
- To provide for amenities or extra items to promote quality of life and independence
- Primarily used to preserve government benefits
- Requires language in the trust that upon the death of the individual, the State is paid back **first** for any government benefits paid during his/her lifetime before distributing rest of trust assets to anyone else

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

Amenities Trusts

Exhibit 12.2

A List of Amenities

- Acupuncture/acupressure
- Advocacy
- Appliances (TV, VCR, stereo, microwave, stove, refrigerator, washer/dryer)
- Bottled water
- Bus pass/ public transportation fees
- Clubs and club dues (record clubs, book clubs, health clubs, service clubs)
- Computer (hardware, software, programs, internet service)
- Courses or classes (academic or recreational)
- Curtains, blinds, drapes
- Dry cleaning and laundry services
- Elective surgery
- Fitness equipment
- Furniture, home furnishings
- Gasoline for automobile
- Haircuts/ salon services
- House cleaning/maid services
- Insurance (automobile, home, and/or possessions)
- Linens and towels
- Massage
- Musical instruments (including lessons)
- Nonfood grocery items (laundry soap, bleach, fabric softener, deodorant, dish soap, hand and body soap, personal hygiene products, paper towels, napkins, Kleenex, toilet paper, any household cleaning products)
- Over-the-counter medications (including vitamins or herbs)
- Personal assistance
- Pet, pet supplies
- Physician specialists
- Private counseling
- Repair services (appliance, automobile, bicycle, household)
- Retail store charge accounts (gift stores, craft stores, hardware stores, pet stores)
- Sporting goods/ equipment
- Taxi cab scrip
- Tickets to concerts or events (for beneficiary and an accompanying companion)
- Transportation (automobile, motorcycle, bicycle, moped)
- Utility bills (telephone, cable TV, electric, heating)
- Vacation (including paying for a companion to accompany the beneficiary)

This list was compiled by Marsha Rose Katz, formerly of the Washtenaw Association for Community Advocacy, and was enhanced by Teryl J. McCoy, a paralegal assistant in the Law Office of Joel S. Welber.

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

1. FREEDOM

2. AUTHORITY

3. SUPPORT

4. RESPONSIBILITY

Freedom

Guardianship

❖ *Liberty*

❖ *Lack of Control*

❖ *Independence* ❖ *Disparagement*

❖ *Autonomy*

❖ *No Power*

❖ *Sovereignty*

❖ *Loss of Rights*

Authority

❖ *Control*

❖ *Mastery*

❖ *Power*

❖ *Rights*

Guardianship

❖ *Lack of Control*

❖ *Disparagement*

❖ *No Power*

❖ *Loss of Rights*

Support

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

Guardianship

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

Responsibility Guardianship

- ❖ *Accountable*
- ❖ *Lack of Control*
- ❖ *Committed*
- ❖ *Disparagement*
- ❖ *Empowered*
- ❖ *No Power*
- ❖ *Decisive*
- ❖ *Loss of Rights*

Desired vs. Current

- Person-centered planning
- Life outcomes
- Build on capacities and abilities
- Behavior as communication
- Choice and control
- Supports and Personal Assistance
- Own Home
- Supports Coordination
- Inclusion and self-determination
- Consumer Satisfaction as test of quality
- Interdisciplinary Teams
- Assessments
- Goals Determined by Deficits
- Behavior Management
- Beds and Slots
- Agency and Provider staff
- Congregate /Program
- Case Management
- Medical Model
- Monitoring and Inspection of care

One of the biggest challenges facing us as we enter the twenty-first century...lies in the overemphasis, even dependency, on power control, paternalism, and, ultimately, coercion.”

Rod Copeland
Commissioner of the Vermont Department
of Developmental and Mental Health

In the real world, people die for their freedoms. In the field of [developmental disabilities], they hold conventions or invite each other to conferences. In the real world, people learn from each other, and protect each other. In the field of [developmental disabilities], one must be licensed to teach, certified to treat, and commissioned to protect. That which is considered to be good in the field of [developmental disabilities] is professionally controlled.

Burton Blatt, 1981

What is least restrictive about the real world derives from thousands of years of human discourse under such diverse leaders as Attila and Lincoln, Pharaoh and Moses, George III and George Washington, Martin Luther and Martin Luther King. What's most restrictive about the world of [developmental disabilities] derives from 200 years of professional interest in pathology rather than the universality of people. Professionals have created much of the need to do something about the problem of too restrictive environments forced upon [people with disabilities]. We have created or been much of the problem, and now we seem anxious to do something, but less to rescue [people with disabilities] than to redeem ourselves, less to obtain their freedoms than to establish ours, less because they need us than because we need them." *Burton Blatt, 1981*