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
180 Duncan Mill Road Suite 600
North York, Ontario M3D 1Z6

People First of Ontario
People First of Canada
Ontario Association for Community Living

Canadian Association for Community Living
Youth Involvement Ontario
Ontario Association for Community Living
“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. ("a ward")
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?
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!
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”
“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
# 1990 Guardianship Filings

<table>
<thead>
<tr>
<th>STATE</th>
<th>NUMBER OF FILINGS</th>
<th>Per 100,000</th>
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<tr>
<td>Washington</td>
<td>2,632</td>
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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
Article 4
General Obligation

5) The Provisions of the present Convention shall extend to all parts of Federal States without any limitation or exceptions
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)
“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. . .

“Guardianship … shall be utilized only as is necessary to promote and protect the well-being of the individual…”

(MCL 330.1602(1))
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
- 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
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 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 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 their full dignity as a fully participating member of the community.

Adopted by the Howell Group of Michigan, October 1994
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.
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 my 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)
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
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.


- New Michigan law also permits PADs for mental health decisions. This is also a preferred alternative to “Kevin’s Law” (court-ordered, outpatient treatment).
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 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 individual. 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
Two Methods: Opting Out of Credit Card Offers

- **Five Year Opt – Out**
  
  Complete form online (secure website)
  
  at: [www.optoutprescreen.com](http://www.optoutprescreen.com)

- **Permanent Opt – Out**
  
  Form must be printed, signed and mailed.
  
  (Five year opt-out may be completed in the interim)

  Call: (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

- **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
- 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, 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)
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
- No Power
- Loss of Rights
Self-Determination

Authority

- Control
- Mastery
- Power
- Rights

Guardianship

- Lack of Control
- Disparagement
- No Power
- 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
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
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, and how they are provided
- Who provides supports
QUALITY OF LIFE

Money

- Direct your budget
- Opportunity to earn money
- Decide how to spend your money
“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 drives 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
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.
Dohn Hoyle
dohn@arcmi.org
1-800-292-7851

Look for us on www.arcmi.org