

**SUPPORTED DECISION
MAKING;
THINKING OUTSIDE OF THE
GUARDIANSHIP BOX**

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WHAT'S GOOD ABOUT GUARDIANSHIP?

- Offers a form of protection and provides some safeguards against abuse
- Provides a format and a standard for decision-making
- Makes it clear who the “decider” is.
- Insures there is someone with authority to act in an emergency
- Provides third parties certainty about the validity of decisions and actions



WHAT'S BAD ABOUT GUARDIANSHIP?

- Loss of legal personhood – “civil death”
 - Loss of independence, self-expression, and possibly integration
 - Loss of dignity of acting on one's own behalf & dignity of risk
 - Learned helplessness, passivity, loss of ambition
 - Loss of civil rights (e.g., vote, associate, choose where to live, accept or refuse medical treatment, etc.)
 - Possible exploitation by abusive guardian
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LEGAL CAPACITY IN ALASKA

- “Incapacitated person”
 - Impairment of ability
 - to receive and evaluate information or
 - to communicate decisions
 - That causes a lack of ability
 - to provide the essential requirements
 - for physical health or safety
 - without court-ordered assistance



LEGAL CAPACITY IN ALASKA, CONT'D

- “essential requirements” for health and safety
 - health care, food, shelter, clothing, personal hygiene and protection
 - without which serious physical injury or illness is more likely than not to occur



ALASKA GUARDIANS' AUTHORITY

- A full guardian of an incapacitated person has the same powers and duties respecting the ward that a parent has respecting an unemancipated minor
- Except:
 - Least-restrictive abode
 - Institutionalize w/o commitment proceedings
 - Abortion, sterilization, removal of organs
 - Withhold life-saving procedures
 - Prohibit voting
 - Terminate parental rights
 - Prohibit marriage or divorce
 - others



GUIDANCE FOR GUARDIANSHIP

- Used only as is necessary to promote and protect the well-being
- Encourage the development of maximum self-reliance and independence
- Only to the extent necessitated by the person's actual mental and physical limitations
- Preferences of ward considered by the guardian



THE JUDGE DECIDES “LEGAL CAPACITY”

- Judge looks at capacity at the time of the court case
 - Capacity to make decisions as a “yes or no” question
 - Assumption: there are right answers and wrong answers to every decision
 - You can either make the right decision or you can't
- Judge doesn't look at support for making decisions
 - Family, friends, employers, mentors, spiritual or religious community
- Judge doesn't look at use of professional services to help with decisions
 - Care coordinators, doctors, property managers, legal advocates, agencies



WHAT IF?

- What if we treated capacity as something that changes with the decision to be made?
 - Low-risk decisions?
 - Decisions someone is good at already?
- What if we treated capacity as something that could be increased with learning, experience, and access to information?
 - Opportunity to fail and try again?
- What if treated decision making as an opportunity to build capacity for higher risk decisions?
 - Structured examination of options and consequences?



WHAT IF WE DID THE LEGAL PART ANOTHER WAY?

- A written plan that gives a blueprint for how different types of decisions are each made:
 - Has more supervision for decisions with more risk?
 - Less supervision for decisions someone is obviously good at on their own?
 - Changes as someone gets more skills and experience?
- What if we could write a legal agreement that built in support from others?
 - Create conditions for setting goals for a meaningful and reasonably safe life?
 - Teams with members who fill different support roles in decision making that is consistent with those goals?



DEFINITION OF SUPPORTED DECISION MAKING

- Relationships, practices, arrangement, and agreements
- Of more or less formality and intensity
- Designed to assist an individual with a disability
- To make and communicate to others decisions about the individual's life.



PRINCIPLES OF SUPPORTED DECISION MAKING

- People do not inherently lack capacity
- Everyone has a will and preferences
- Will and preferences can be expressed by the person
 - understood (interpreted) by others who know the person well & are in a voluntary, trusting and committed relationship with the person



PROMOTES EQUALITY

- We all use Supported Decision Making on a daily basis
- Think of a recent decision that you made with the assistance of someone else.
 - Why did you need the assistance?
- Legal capacity standard applied to all people?
- Support for decision making protects equality of rights
 - Needing more or different help, or structured process doesn't justify unequal treatment



PROVIDES ACCOMMODATION

- Alteration of a way of doing things that allows a person with a disability to have equal access to opportunities afforded to people without disabilities
 - Understand information, issues, and choices
 - Focus attention in decision making
 - Weigh options
 - Ensure decisions are made on their own preferences
 - Interpret and/or communicate decisions to other parties




IMPLEMENTS INDIVIDUALIZATION AND AUTONOMY

- Consistent with public policy and with our community values:
 - Reflects unique needs for support
 - Maximizes individual potential
 - Includes individuals in the community to the extent they choose
 - State and Federal Rules: Person-Centered and Person-Directed choices about type of services, settings and locations, and personnel



PROTECTS AGAINST ABUSE AND NEGLECT

- Team process means many sets of eyes and minds
 - Greater community engagement increases visibility and accountability
 - Self-Advocacy skills improve
 - Guide for the future protection
 - 1930's average life expectancy for person who experiences I/DD was 22 years old; now 70 years old
 - Blueprint of a process and structure for independence
 - Important information about communication methods, decision making abilities, preferences, supporters
 - Historical record of decision making to guide if guardianship becomes necessary
 - Office of Public Advocacy report 2/2017 (over 1500 in FY 2016)
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WHAT'S ALREADY IN THE TOOLBOX?

- Advanced Healthcare Directives
 - Have specific language describing roles
- Financial plan/Conservatorship
 - Order can limit authority to specific property or accounts
 - ABLE Account
- Powers of Attorney
- Individualized Plan for Employment with DVR
 - Must ensure that person exercise informed choice, with support and assistance if needed
- Consent for Medical Care
 - Must be informed consent with assistance if needed
- Transition-age youth at school
 - Individualized Education Programs have plans for adulthood
- Medicaid services (and Plans of Care)
 - Require person-centered planning
- Representative Payee Contract
 - For Social Security benefits
- Limited Guardianship backstop for high risk decisions

EXAMPLE: JOHN

- 40 years old
- Owns his own condo and car
- Works 30 hours a week as janitor (for 10 years)
- Gets Social Security benefits
- Has a representative payee appointed by Social Security office
- 6 brothers and sisters; 5 local (supporters)
- **ALMOST LOST HIS CONDO**

INSTEAD OF FULL GUARDIANSHIP . . .

- Ticket-to-Work Coordinator
 - Made a Path to Work plan so he doesn't lose benefits
- Older sister has Power of Attorney over some finances
 - Can get all bills and banking information from rep payee or bank
 - Her signature is required for withdrawals from savings account

INSTEAD OF FULL GUARDIANSHIP . . .

- “Reasonable Accommodation” from condo association
 - Crisis plan if he needed help
 - Phone list of supporters
 - What each supporter would do to help him choose what he needed
- Checking account with fixed amount in it each month
 - Rep payee would send accounting to John and to older sister

INSTEAD OF FULL GUARDIANSHIP . . .

- Limited guardianship order for condo membership duties (the unacceptable risk)
 - Younger sister who he gets along best with
 - All meeting agendas and notices
 - Attend condo association meetings with him
 - Property management company contact
 - No legal action without notice to her

WHAT IS MISSING FROM OUR TOOLBOX?

- One Ring To Rule Them All . . . (a nod to Tolkien geeks)
- A written agreement that:
 - Lists the team members and roles
 - Can attach authorizations for release of information
 - Describes life goals and preferences
 - Describes how big decisions get made (in light of goals)
 - Refers to other attached documents, if needed
 - Gives notice to third parties
- Do we need a special education bill like Texas?
 - <https://legiscan.com/TX/text/SB748/2017>



SPECIAL EDUCATION PLANNING

- IEP Transition goals for self-advocacy
 - Objective can be Supported Decision Making Agreement
 - Context for teaching important skills
 - Measurable
 - Incorporates info from Present Levels
 - Can be used for Exit Summary
- IEP Writing goal
 - SDM process includes structured composition
 - Individualized
- IEP Social/Emotional Learning goal
 - Engaging supporters
 - Directing support



QUESTIONS?

