What is Informed Choice for People with Intellectual and Developmental Disabilities?

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What Will We Cover?

• Current Context
• Constraints to Choice Making
• Guardianship Data on People with ID/DD in Georgia
• Supported Decision-Making as an Alternative to Guardianship
• Overview of Reforms
• Moving Forward
In the field of human services there is an increasing emphasis on empowering people to make more choices about their lives and the services they receive

- In 2016, there were 252 publicly funded self direction programs across the country that totaled approximately 1 million people, including those who are elderly and have developmental/other disabilities

- The CMS Settings Rule (2013) reinforces the importance of Individual choice in waiver-funded services including choice of home, room mates, staff, etc.
The Affordable Health Care Act included a number of provisions that emphasized self direction including the requirement that all federal agencies develop self-direction guidelines.

In the health care field, there is an increasing emphasis on “shared decision-making”.

Part of the CMS rule includes requirements for person centered planning that focuses on the Individual’s goals, is conducted in language that is accessible to the Individual, is held in a location of the person’s choosing, and that is responsive to changing needs.
Constraints to Choice Making for People with ID/DD
Some People with ID/DD Have Challenges Making Decisions

- Difficulty understanding and remembering advice and information
- Need for supports (e.g., visual explanations, simplified and/or accessible materials)
- Difficulty communicating information or decisions, or need for communication supports (e.g., augmentative communication signs, pictographs, equipment)
- Need support to learn and carry out decision-related tasks (e.g., following health care routine, balancing checkbook, navigating neighborhood)
Challenges facing people with ID/DD have lead to substituted decision-making through various forms of guardianship. Substituted decision-making has the following impact:

- Loss of the ability to make important life decisions without the approval of the guardian
- Erosion of the Individual’s ability to develop the skills necessary to make decisions
- Exclusion from communities because of the inability to enter contracts, make medical decisions, spend money, etc.
Types of Substituted Decision-Making

- Representative Payee
- Health Care Proxy
- Education Decision-Maker

- Limited Guardianship
- Durable Power of Attorney

- Full Guardianship
- Conservatorship
Problems with Presumed Incompetence

- People may not be included in conversations where important decisions are made about their lives.
- People don’t develop the skills necessary to participate in decisions (e.g., Individual service plan) because they have to rely on others.
- When they want to make a purchase, get married, open a bank account or enter into a legal agreement, people have to ask permission.
- Loss of “dignity of risk”
- Doctors, dentists and other medical professionals may not provide treatment unless the person has a guardian because of concern the person can not make an informed decision.
National Core Indicators (NCI) Data on Guardianship in Georgia for People with ID/DD
National Core Indicators Adult Consumer Survey

- Individuals who receive at least one service beyond case management from the IDD agency participate in the survey
- Face-to-face survey with the person receiving services
- Survey includes three main parts:
  - Background information – largely collected from state records
  - Section I – Subjective questions *only* the person can answer
  - Section II – Objective questions can be answered by a proxy when needed
Georgia Response Rates 2016-17

- 64% valid Section I
- 100% valid Section II
- 462 total survey complete
Topics Addressed in Adult Consumer Survey

- Individual Outcomes
- Health, Welfare and Rights
- System Performance
Types of Guardianship and Guardians

Level of Guardianship (N=456)
- Limited guardianship (0%)
- Full guardianship (16%)
- Has guardianship, level is unknown (1%)
- No guardianship (83%)

Type of Guardian (N=76)
- Employee of the state, 9%
- Friend, 1%
- Family, 89%
Guardianship Trends

Has a Legal or Court Appoint Guardian

- **12%**
  - 2014
- **17%**
  - 2015
- **17%**
  - 2016

Compared to other states, Georgia has consistently lower rates of guardianship each year.
# Comparison by Age, Level of ID and Need for Behavior Support

## Average Age
- **Age of 41** had no guardian (N=378)
- **Age of 38** has a guardian (N=76)

## Needs Behavior Support
- **28%** no guardian (N=375)
- **34%** has a guardian (N=76)

## Level of ID

<table>
<thead>
<tr>
<th>Level of ID</th>
<th>No guardian (N=76)</th>
<th>Has guardian (N=369)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>11%</td>
<td>21%</td>
</tr>
<tr>
<td>Moderate</td>
<td>9%</td>
<td>15%</td>
</tr>
<tr>
<td>Severe</td>
<td>11%</td>
<td>21%</td>
</tr>
<tr>
<td>Profound</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Has ID, level unknown</td>
<td>12%</td>
<td>11%</td>
</tr>
</tbody>
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Residence: Those With and Without Guardians

- Group setting: 23% (N=321) vs. 36% (N=68)
- Own home: 15% vs. 5%
- Parent or relative's home: 47% vs. 47%
- Foster or host home: 14% vs. 12%
- Other: 1% vs. 0%

*sig at .05
Primary Means of Expression**

Spoken
- 78% no guardian
- 56% has a guardian

Gestures or Body Language
- 19% no guardian
- 35% has a guardian

Other
- 2% no guardian
- 9% has a guardian

No guardian N=376  Has Guardian N=77

**Sig at .01
# Guardianship and Community Participation and Leisure

<table>
<thead>
<tr>
<th>Category</th>
<th>No Guardian (N=232)</th>
<th>Guardian (N=32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to go out and do the things s/he likes</td>
<td>89%</td>
<td>81%</td>
</tr>
<tr>
<td>Has enough things s/he likes to do at home*</td>
<td>86%</td>
<td>69%</td>
</tr>
</tbody>
</table>

*sig. at .01
Georgia has lower rates of Individuals under guardianship than across other states that conduct the NCI:

- Few significant differences found among those with and without guardianship
- Those with guardianship were:
  - More likely to live in a group setting and less likely to live on their own
  - More likely to be non-verbal
  - More likely to need support for behavior issues
Supported Decision-Making

Supported Decision Making (SDM) is a right not only to make decisions (with support if needed) but to have those decisions recognized and honored. SDM recognizes the use of all types of communication.
We All Need Support to Make Decisions

- Life is complex and we all need help making decisions from a range of sources, including:
  - Families
  - Friends
  - Lawyers
  - Doctors
  - Counselors
  - Clergy
  - Internet
  - Support groups

- People with disabilities may need more intentional support to make decisions
What is Supported Decision-Making (SDM)?

Supported Decision-Making is relationships, arrangements, and agreements that assist a person with a disability to make and communicate important decisions.

People with disabilities may choose one or more trusted support persons to assist them including:

- peer support
- community support networks
- natural supports (family, friends) or
- representatives (using a representation agreement)
Supported Decision-Making

- Supports an Individual with a disability to make his or her own decisions
- Is accessible and available to all – lack of resources should not be an excuse
- Is based on the will and preferences of the person (and not on presumed best interests)
- Promotes self-advocacy, self-determination, and independence
  - Provides legal recognition of the support person(s) chosen by the person. The person has right to terminate or change supporter. Others can verify and object if supporters are not following person’s preferences
  - Ensures availability of supporters for important decisions of legal relevance
  - Provides informal support for everyday decisions
  - Involves flexible support tailored to Individual need and importance of decision
  - Assistance with gathering information, understanding options, and communicating with third parties
## Supported Decision Making vs. Guardianship

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<thead>
<tr>
<th><strong>Guardianship</strong></th>
<th><strong>Supported Decision Making</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Decision making rights are removed from the Individual and given to another Individual</td>
<td>• Individual keeps all decision making rights</td>
</tr>
<tr>
<td>• Guardians make decisions <em>for</em> the Individual with ID/DD even if the guardian consults with the Individual</td>
<td>• Individual makes decisions <em>with</em> help from those they select (even when extensive support to communicate and express decisions is necessary)</td>
</tr>
<tr>
<td>• Guardianship is rarely removed or reduced</td>
<td>• Allows change as Individual’s preferences/needs change</td>
</tr>
<tr>
<td>• Decisions made are in the best interest of the Individual (evolving now to Individual’s preferences)</td>
<td>• Individual’s preferences more important than what is in the best interest of the Individual</td>
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Overview of SDM Reforms Nationally

- Two states (Texas and Delaware) have passed Supported Decision Making statutes that require third parties to honor Supported Decision Making Agreements and relieve supported decision makers from liability for doing so. Four additional state legislatures are actively considering similar legislation.

- Court decisions (Jenny Hatch and other litigation)

- National disability organization policy statements (i.e., AAIDD, Arc, American Bar Association, National Guardianship)

- SDM pilot projects and evaluations
Jenny Hatch Case Provided Momentum for Supported Decision-Making

- Mother & step-father of 29 year old woman with Down syndrome petitioned for guardianship. Jenny objected to guardianship and decisions parents were making for her (group home, sheltered workshop, no phone, no laptop, no visits with friends). At trial, Jenny presented her preferences and supporters she utilized for decisions.

- Judge named a couple Jenny chose to support her as temporary limited guardians for 1 year, with goal of transitioning to SDM. Temporary guardianship expired in August 2014.

Jenny Hatch Justice Project website: http://jennyhatchjusticeproject.org/trial
In 2016, AAIDD adopted & Arc Board passed the Autonomy, Decision-Making Supports and Guardianship Position Statement.

**Statement:** All Individuals with intellectual and/or developmental disabilities (I/DD) have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with Individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities UN CRPD, 2006). The personal autonomy, liberty, freedom, and dignity of each Individual with I/DD must be respected and supported. Legally, each Individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each Individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.
Joint AAIDD Arc Position Statement

**Position excerpt:** State laws should be reformed to prefer less intrusive alternatives to full guardianship, including limited guardianship, limited (and revocable) power of attorney or health care proxy, specifically tailored to Individual need. These alternatives should always be considered first.

Regardless of their guardianship status, all Individuals with I/DD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order.
Take precautions so people understand they can specify those decisions they want support with and those decisions they want to make without using SDM.

When more than one decision supporter is selected, SDM agreement should describe how consultation is to work.

“Shared Living” is a model that offers people, who use SDM, a community member they trust to serve as a decision supporter.
Moving Forward
Support Decision-Making

- Help families to learn about alternatives to guardianship
- Build decision supports into Individual plans
- Assist people to develop circles of support to ensure there are people in their lives who can assist them to make decisions
- Provide people with information in accessible formats to help them understand the consequences of their decisions
- Assume that all people can make decisions in their own lives with the support of people who know and care about them
- Include people in all decisions not just simple ones (e.g., what to wear, eat, where to go)
- Provide information and training to direct support staff to better understand informed decision making
Questions and Feedback
Thank you