

Building Capacity for Exercising Choice: A Supported Decision-Making Approach

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What do Waiver Recipients Choose?

▶ **JUST ABOUT EVERYTHING!**

- ▶ A person receiving Waiver services can and should choose:
 - What services to receive
 - Who to receive them from
 - Where to receive them



How do people make decisions?

- ▶ Make a Pro/Con list?
 - ▶ Trust your instincts?
 - ▶ Ask others for input?
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- ✓ Is this different for big vs. small decisions?
 - ✓ Is this different for people with disabilities?

Understanding Capacity

- ▶ Capacity is not easy to assess or measure
- ▶ Capacity may change over time based on experience or situation.
- ▶ A combination of different supports may be required to provide the best assistance.
- ▶ Lack of opportunity to make decisions can prevent people from developing capacity.



Capacity Can Change

- ▶ Capacity is not black and white.
- ▶ A person may be able to make some decisions but not others.
- ▶ Or they can make some decisions at some times, but not others.



The challenge in practice....

- ▶ What role and responsibilities do “helpers” have to support decision making?
- ▶ For whom do we have the greatest concern?
- ▶ What about the role of families?
- ▶ How does guardianship fit in?
- ▶ What should support look like?



And the result is....

▶ In DC....

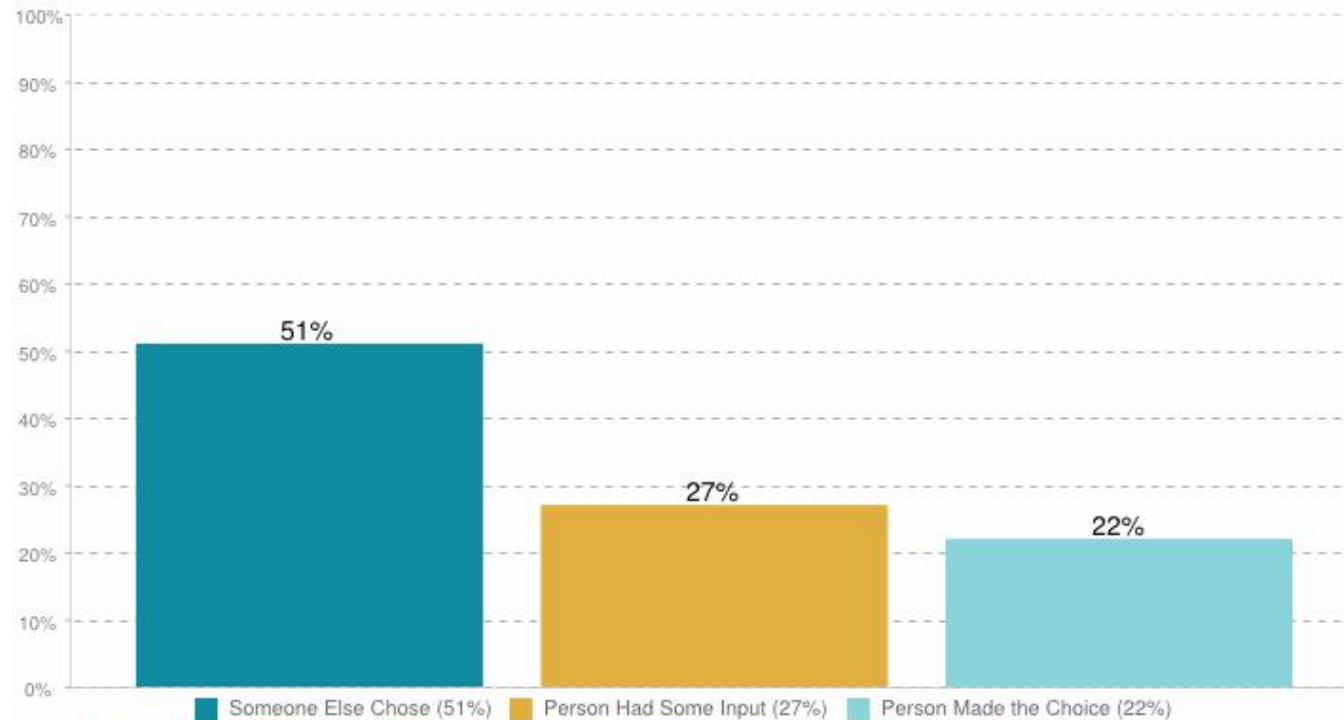
- Over 80% of the “class members” have at least a limited guardian that makes decisions.
- Out of approximately 2200 people receiving services, less than 1% are identified as able to make decisions for themselves.

▶ Nationally....

- The CQL database with over 8,200 interviews, only one-half or fewer of the people were exercising choices about home, work, goals or services in a way that was meaningful to them.



Chose Home



Indicator: The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, what to spend money on, and social activities.

Year(s): 2011-12

State: AL, AR, AZ, CT, GA, HI, IL, KY, LA, MA, ME, MEORC, MI, MO, NC, NJ, NY, OH, PA, SC

Filter: None

Additional Information: 1) Total Number of Respondents = 8130

2) Proxy respondents (e.g., a family member) were allowed to answer this question

3) In 2011-12, persons living in the family home were not asked this question.

National Core Indicators. Chart Generator 2011-12. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved on 09/11/2013 from the National Core Indicators Website:

<http://www.nationalcoreindicators.org/charts/>.

Please Note: This item is used by some states to meet the following CMS Waiver Assurance/Sub-Assurance- Service Plan: Participants are afforded choice between waiver services and institutional care, and between/among waiver services and providers.

Supported Decision–Making

- ▶ UN Convention on the Rights of Persons with Disabilities (CRPD), esp. Article 12
- ▶ Supported vs. Surrogate Decision–Making
- ▶ Provides for Meaningful Involvement by the Person needing support in Decision–Making
- ▶ Identifies Guardianship as the Most Restrictive Intervention



From Protection and Surrogacy to Support and Real Choice

- ▶ Understand the distinction between the two approaches (make for vs. make with)
- ▶ Implement guardianship and other support in a way that respects the person's perspective.
- ▶ Use “Substituted Judgment” before “Best Interest”
- ▶ Benchmark practices to how people make decisions—whether or not they have disabilities.



Supporting Decision Making

- ▶ Respect people as the decision-maker
- ▶ Look to develop each person's decision-making voice
- ▶ Recruit support as needed
 - Informal (friends/family/advocate)
 - Formal (legal – conservator/guardian)
- ▶ Ensure access to options
- ▶ Make room for mistakes



Decisions that cause concern

Health and Medical Decisions

- ✓ Emergency
- ✓ Non-emergency

Financial

Relationships

Personal Care



“Enemies” of Good Decisions

- ▶ Addressing the wrong question
- ▶ Looking only for information that “confirms” our thinking
- ▶ Emotions
- ▶ Being too confident
- ▶ Lack of engagement
- ▶ No creative exploration of options



Learning from stories.....

- ▶ Scenario One – Albert “I want it my way!”
- ▶ Scenario Two – Bernie “I haven't a clue, but I’m good at faking it”
- ▶ Scenario Three – Lynette “ I don’t hear very well (literally and figuratively)
- ▶ Scenario Four – Maree Lou “ I only know one way and I’m scared”
- ▶ Scenario Five – Denice “ I don’t know what I want, but I don’t like what I have”



Tools.....

- ▶ Effective Communication
- ▶ Peer Support
- ▶ Practical Experiences
- ▶ Life Coaching

The One SIMPLE Goal of Supported Decision-Making

Each person is always part of every decision about his or her life.

This requires assisting the person to make as many of his or her life decisions as possible and desired, to have as much control over his or her life as possible.

The result will be a life that reflects the person's unique qualities as a person.



Decision Support in Action

- ▶ One size does not fit all
- ▶ Person is in control of relationship
- ▶ Customize actions to and with the person
- ▶ Find lots of tools for your toolbox
- ▶ Be flexible and try multiple ways



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