



For people with intellectual
and developmental disabilities

Welcome to today's panel!

- **First time using Webex?**
 - You can communicate with other attendees or the host in the **Chat Box** and seek technical assistance if needed.
 - You can type questions about the material presented in the **Q&A** section.
- Today's webinar will be **recorded and shared publicly**. Please keep this in mind when sharing information and experiences during the webinar.



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Supported Decision-Making: What is It and What Do You Need To Know to Get Started?

Tina Campanella, CEO

Quality Trust for Individuals with Disabilities

Bonnie Nelson, State Restoration Project Manager,
The Arc of North Carolina

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The Promise and Potential of a Supported Decision Making Approach

Tina Campanella, CEO
Quality Trust for Individuals with Disabilities
September 2015

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Supported Decision-Making

- UN Convention on the Rights of Persons with Disabilities (CRPD), esp. Article 12
- Emphasis on legal capacity as a “right”
- Provides for Meaningful Involvement by the Person needing support in Decision-Making
- Identifies Guardianship as the Most Restrictive Intervention



Using a Supported Decision Making Approach means....

- People retain their rights,
- Have full control of decisions impacting their life, and;
- Get assistance with decision making when needed.

What happens now?

- Little to no emphasis on “teaching” decision making skills
- Low expectations for children or adults to be involved in decision making in meaningful ways
- Superficial use of “preferences” in structured programming
- Bias toward the use of substituted decision making as a primary support



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Margaret “Jenny” Hatch

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Defining the Challenge....

- How do people become good decision-makers?
- What role and responsibility do professional “helpers” have to support decision making?
- What about the role of families?
- What should support look like?
- How does guardianship fit in?



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Think about Decision Making....

- Many decisions every day
- Some big, some small
- What's our process?
- Is this a science or art?
- Who decides if our decisions are “good”?

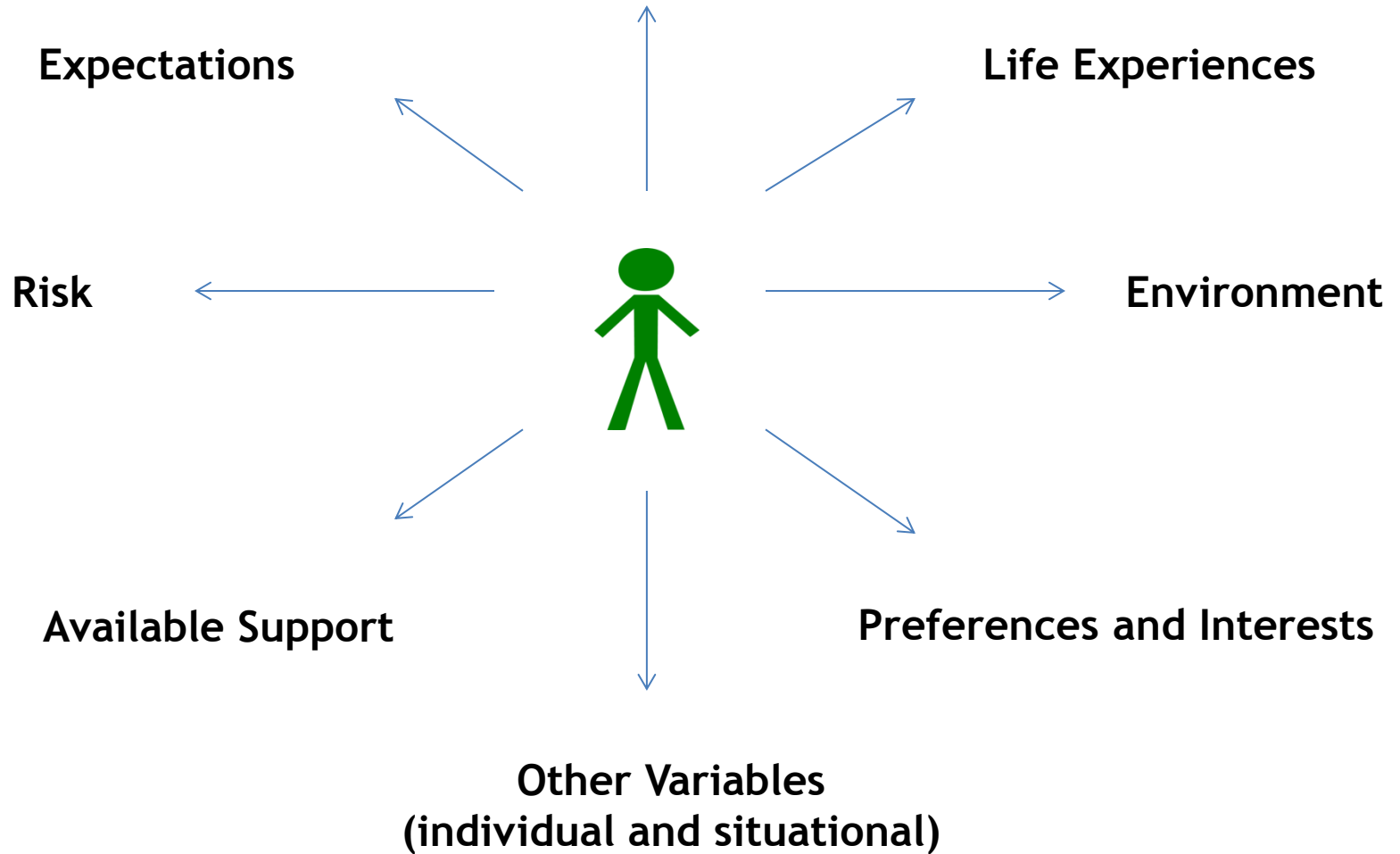


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So, what do we really know?

- Human decision making is
 - Personal
 - Often flawed
 - Influenced by culture, values, others, personal experience and more!

Skills/Capacity





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Watch out for Limiting Beliefs

- Intellectual capacity will always be limited
- People with certain needs (disabilities or diseases) need to be controlled, in certain environments, certain therapies, etc.
- Risk can be eliminated
- Condition is more important than humanity
- People will never..... (fill in the blank)

People are people!!!!

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Learning to Listen

- Not being able to talk doesn't mean you don't have anything to say
- Not knowing how to express yourself should not mean you are ignored
- Everything people do communicates
- Our job as supporters is to move beyond assumptions
- Try different many different approaches until one works



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Effective Personal Supports

- Keeps the focus on people first
- Requires understanding of the unique preferences, goals and desires for each person
- Bases the support process on the details of a person's situation



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Supporting Decision Making

Starts with...

- Respecting people as the decision-maker
- Helping to develop each person's decision-making voice
- Recruiting support as needed
 - Informal (friends/family/advocate)
 - Formal (legal - conservator/guardian)
- Ensuring access to a full range of options
- Making room for risk, dignity and mistakes

From Protection and Surrogacy to Support and Real Choice

- Understand the distinction between the two approaches (do for vs. do 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.
- Acknowledge that guardianship by definition is a protection and removes individual rights



National Resource Center on Supported Decision Making (SDM)

- Funded in 2014 by the Administration on Community Living
- Focused on Research, Training and Information Sharing about SDM
- Addressing the issues of people who are aging and people with disabilities
- Linking efforts at reform throughout the country
- Check it out

www.supporteddecisionmaking.org



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A Vision for The Future

- Involve youth in decisions early
- Prepare to support decision-making at age 18
- Use the support approach that imposes the least restriction on rights
- Benchmark to the process and experience of typical young people
- Always plan ahead - documenting and updating plans as the person's preferences develop



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What you can do...

- Stand by people as they are developing capacity
- Minimize focus on formal capacity evaluation
- Emphasize experience based assessment of ability
- Make sure people get every opportunity to learn and/or participate in decisions
- Defend person's ability to take control in any settings and situations where it's possible

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Contact Us....



www.dcqualitytrust.org

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<https://www.facebook.com/QualityTrust>

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RESTORATION AND ALTERNATIVES TO GUARDIANSHIP IN NORTH CAROLINA

A PROJECT FUNDED BY THE NC DEPARTMENT OF HEALTH AND
HUMAN SERVICES AND ADMINISTERED BY THE
LIFEGUARDIANSHIP DIVISION OF THE ARC OF NC 2013-2015

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Project Goals

- 1) To provide Information, Education, Consultation and Technical Assistance to as many people as possible through direct and indirect contact;
- 2) To conduct 8 Statewide Training Conferences over a 2-year period of time as well as other smaller group and individual training as time permitted;
- 3) To notify as many parents, state and private agencies and individuals with disabilities that consultation, technical assistance and training was available at no cost. **Assistance**

Goals (cont'd)

- 4) To conduct assessments of approximately 700 Arc of NC proteges using the NC Capacity Questionnaire and other forms used by LIFEguardianship Specialists to assess readiness for restoration of rights and alternatives to guardianship;
- 5) To disseminate information about the Project through mailings, exhibits at other conferences, small group meetings and our own training conferences as well as internet postings;
- 6) To train as many Arc LIFEguardianship staff as possible restorations, alternatives to guardianships and Supported Decision-Making;

Goals(cont'd)

- 7) To restore rights to as many people as were assessed ready for restoration as possible;
- 8) To develop a training curriculum/module on Alternatives to Guardianship, Restoration of Rights and Supported Decision-Making;
- 9) To identify two Gaps in Services in NC that need to be addressed.

Needless to say, many gaps were noted, but the two selected were a) the need for additional structure and training in SDM and b) the need for legislation to make SDM a legal option for families.



What was done to promote this in the future?

Three local chapters of The Arc of NC were chosen in FY 2015 to conduct mini-projects employing principles of Supported Decision-Making in concert with a designated LIFEguardianship Specialist in their area who was involved in doing restorations of their Proteges' rights.

What was done to promote this in the future?

- a) Funding was made possible by Restoration Project funds and joint utilization of Arc staff from the State and Local Arcs.
- b) These 3 local Arcs were to recruit volunteers to work with proteges whose rights were restored while they were supported by State and Regional LIFEguardianship Specialists.
- c) Then the people whose rights had been restored who would no longer be supported by LIFEguardianship were to begin being supported by the Local Arcs and the Volunteers, families and friends recruited utilizing the principles of SDM as trained by the LIFEguardianship Restoration Project Training Conferences.



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Future (cont'd.)

2) Legislation was introduced in the NC General Assembly to make Supported Decision-Making a legal option for NC families as an Alternative to Guardianship.

- It was referred to a Committee for Study.

3) A study committee was established in conjunction with the Social Work Department of the University of North Carolina at Chapel Hill entitled “Rethinking Guardianship” and many of the people in NC who are concerned about Guardianship Alternatives are on it including myself and Representative Jean Farmer-Butterfield who is also the Senior Director of LIFEguardianship for the Arc of NC.



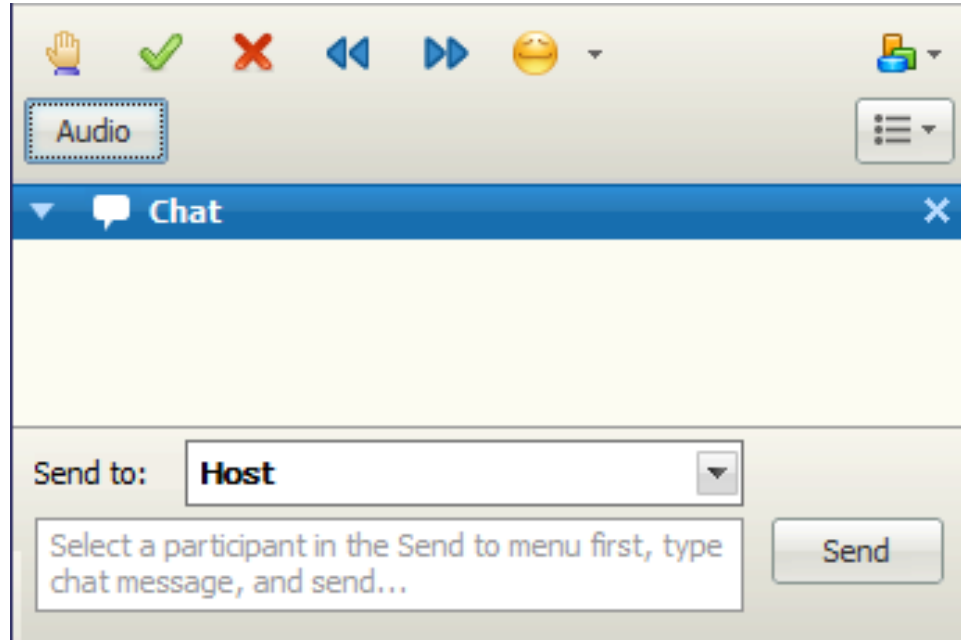
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Future (cont'd.)

4)The Arc of NC joined together with the NC First in Families organization to apply for a Supported Decision-Making State Mini-Grant from the DC Quality Trust organization. That grant has been funded and I would like to briefly show you some of the highlights:

Questions?

Please raise your hand and we will call on you OR type your question into the chat box.





Next Webinar

**Wednesday, October 21st, 2015, 2:00-3:00 PM Eastern
Employment**

If you have any questions, please contact us at
futureplanning@thearc.org