

Summary Paper: ASAN's Invitational Summit on Supported Decision Making and the Transition into the Community

Purpose

This paper gives an overview of the Autistic Self Advocacy Network's summit, "*Invitational Summit on Supported Decision Making and the Transition to the Community*." It discusses the purpose of the summit, the structure of the summit, and the outcomes and conclusions reached by its end. It will be followed at a later date by a more in-depth paper discussing what we learned about supported decision making from the summit and its attendees and what strategies we can recommend.

Introduction

Community integration, the ability to make choices, and quality of life outcomes are, for people with disabilities worldwide, very closely linked. Multiple peer-reviewed journal articles, studies, and reports found that people with disabilities are happier, healthier, and more productive when they live in the community and control their own lives.¹ Despite this, many people with disabilities are routinely denied their most basic civic rights. Their power to make decisions is given to someone else in a process known as *guardianship*. They are confined in institutional settings that restrict their movement and limit their choices. Disability advocates worldwide have proposed an alternative to guardianship: assistance from trusted supporters that does not take away the person's right to make decisions. This is known as *supported decision making*. Our community also advocates for closing institutions and replacing them with cost-effective, community-based options.

The Autistic Self Advocacy Network² hypothesized that supported decision making arrangements may aid in the processes of deinstitutionalization and community integration. To that end, we held a two day strategic summit. The summit discussed supported decision making in depth and the best strategies for using it to bring people out of restrictive settings.

1 Michael L. Wehmeyer and Susan B. Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination, Education & Training in Mental Retardation & Developmental Disabilities* (2003); Tina M. Anctil, et al., *Academic Identity Development Through Self-Determination: Successful College Students with Learning Disabilities*, 31 *Career Dev. For Exceptional Individuals* 164 (2008); I. Khemka, L Hickson, & Gillian Reynolds (May 2005). *Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*. *American Journal on Mental Retardation*, 110(3), 193-204; Michael L. Wehmeyer and Michelle Schwartz, *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 *Exceptional Children* 2, 245-255 (1997).

2 The Autistic Self Advocacy Network is a United States based 501(c)(3) not-for-profit advocacy organization created by and for Autistic people. Its mission is to advance the social and civil rights of Autistic people and other individuals with disabilities. For more information on ASAN and its work, visit <http://autisticadvocacy.org/>.



The Autistic Self Advocacy Network is a 501(c)(3) nonprofit organization run by and for autistic people. The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

ASAN's Invitational Summit on Supported Decision Making and the Transition into the Community

The summit was held on October 18th and 19th, 2016, at American University, Washington College of Law. The summit was invitation-only in order to foster productive discussions between people with relevant expertise. 45-47 people attended our summit, 10 of which came from countries other than the United States. Although ASAN is a United States nonprofit, the supported decision making movement is intersectional and international. We felt that if we had a more diverse group, we could learn from one another and create strategies which could work in multiple countries and contexts.

Structure of the Summit

The summit was divided into four topics: **Healthcare, Relationships and Natural Supports**,³ **Housing, and Long Term Services and Supports**.⁴ A person with a disability who wants to enter the community from an institution usually needs support in one or several of these areas. Each topic consisted of three sections:

- (1) A five-person panel of experts who described their work and experience around the topic as it relates to supported decision making
- (2) Breakout discussion groups during which smaller groups of attendees discussed the topic in greater detail
- (3) Breakout presentations during which each breakout group presented the results of their discussion to all other attendees.

We also held an **Introduction** panel and a **Wrap-Up** panel.

Introductory Panel

Our panelists were **Liz Weintraub**, Self-Advocacy Specialist at the Association of University Centers on Disability, **Jonathan Martinis** of the Burton Blatt Institute, who helped found the National Resource Center for Supported Decision Making, **Kristen Booth Glen**, a former Judge who delivered the landmark *In Re: Guardianship of Dameris L.* ruling, and **Eric Rosenthal**, law professor and Executive Director of Disability Rights International.

The Introductory Panel's primary three themes were: (1) deinstitutionalization and its historical context; (2) the history of the supported decision making movement; and (3) how supported decision making could be used as a way to integrate people with disabilities into their communities. For example, Jonathan Martinis compared the current system (where every provider dispenses services for the person in a vacuum and assumes certain things about the person) to a potential coordinated support system (which comes up with services based on the decisions of a team, which includes the person with a disability in a central role).

Healthcare

Our panelists were: (1) **Andrea Parra**, the Executive Director of PAIIS, a human rights clinic in Columbia, and current Practitioner In Residence at the Washington College of Law; (2) **Morénike Giwa Onaiwu**, an autistic self-advocate with children who have significant health care needs; (3) **Clarissa Kripke**, a healthcare practitioner who specializes in care for those with developmental disabilities and the Director at the Office of Developmental Primary Care in California; (4) **Nicole LeBlanc**, a Policy Intern at the Association of University Centers on Disability (AUCD); and (5) **Lynne O'Hara**, Executive Director at the WITH Foundation (formerly the Special Hope Foundation).

³ Relationships and Natural Supports refers to the ordinary relationships in one's life, such as one's friends, family, religious leaders, and community. Supporters are often drawn from this group of people.

⁴ Long Term Services and Supports (LTSS) refer to services delivered over a long period of time (as opposed to acute medical care or crisis care, which is delivered for a brief period of time and only when needed) that support a person with a disability in their day to day lives. Examples include (but are not limited to) personal assistant services, occupational therapy, breathing and ventilation services, supported employment, etc.

The following were the major themes and ideas of the Healthcare discussion:

All supported decision making systems, where they exist in law, should include funding for teaching both the person and their supporters about their health care needs. Ensuring people can understand their health situation and give informed consent is one of the hallmarks of effective supported decision making.

Successful healthcare for people with disabilities with significant health care needs, such as those who have been in institutions for a long time, requires a network of providers who understand these conditions. We suggested connecting doctors who have considerable experience with disabled patients with those who do not.

A country's broader health care and disability policies have a significant impact on the viability of supported decision making in that country. When we talked about health care, we also talked about all of the other topics and their relations to SDM. We should advocate for policies that allow people to receive government funding for health care in any setting, not just institutional settings.

Relationships and Natural Supports

Our panelists were: (1) **Sehnaz Layikel**, president of RUSIHAK, Turkey's only rights-based mental disability advocacy organization; (2) **Kapka Panayotova**, founder and Executive Director of the Center for Independent Living in Bulgaria; (3) **Emily Titon**, President of AutCom, TASH board member, and member of the Rhode Island Developmental Disabilities Council; (4) **Monique Wilson**, committed parent advocate and coordinator for New Jersey's Statewide Parent Advocacy Network (SPAN); and (5) **Paula Mendez Azuela**, Human Rights Advisor for the Mexican Supreme Court.

The following were the major themes and ideas of the Relationships and Natural Supports discussion:

Peer support and engagement from other persons with disabilities is critical to supported decision making. If a person with a disability can see a peer making a decision successfully, they can learn how to do it themselves. The attendees supported robust leadership development and train the trainer programs which teach people with disabilities how to advocate for themselves.

The attendees disagreed on whether or not there should be paid supporters (i.e. whether there should be persons paid to help people with disabilities understand and make decisions). Some summit participants proposed a network of paid supporters as complex as some of the *guardian ad litem* networks in the United States, while others opposed any paid SDM supporter.

The attendees spoke extensively about what form a person's supporters should take. They found that there should be multiple supporters whenever possible, and the supporters should have healthy relationships with the person, without conflicts of interest. The ideal situation is a group of 3-5 people, all of whom have different expertise.

Many of the attendees felt it was important to introduce people who do not have many relationships to their communities. They discussed many different ways of doing so, from introducing people to community gathering places (such as churches and other community organizations) to more gradual introduction of the person to their neighbors and communal spaces in their neighborhoods.

Housing

Our panelists were: (1) **Hana Solařová** of Lumos, an international organization dedicated to the deinstitutionalization of children; (2) **Max Barrows** of Green Mountain Self Advocates, a self advocate group which promotes autonomy and self-advocacy for people with disabilities; (3) **Gail Godwin** of Shared Support Maryland, an agency which provides support in the community to people with significant disabilities; (4) **Bob Fleischner** of the Center for Public Representation, who spearheaded a project to use SDM to obtain affordable housing for people with disabilities; and (5) **Leslie Salzman**, a renowned legal scholar on guardianship and SDM and Clinical Professor at Benjamin Cardozo School of Law.

The following were the major themes and ideas in Housing:

Landlords could be either our greatest allies or our fiercest opponents in access to affordable housing. The summit attendees discussed case examples where landlords ranged from extremely helpful to an obstruction. They proposed a variety of solutions, including engaging the active landlord community around issues of disability and having housing agencies issue guidance to landlords on SDM.

Lack of affordable, accessible housing is a significant barrier to deinstitutionalization. In many countries, there are few or no affordable housing options available. One solution may be working with other rights-based groups who advocate for affordable housing, rather than concentrating solely on disability-specific issues.

Housing should be separate from support services. Supported decision making arrangements can aid in this separation by helping the person speak directly to property owners and landlords about the type of home they need, independently of getting support services.

The best way to move someone with a significant disability from an institution into the community may be through methodical use of supported decision making. Many participants described successful models by which the person's likes and dislikes are incorporated into the final choice of housing. These models may take a long time, but service providers must prioritize the person's autonomy over the amount of time it takes to determine what they want.

Long Term Services and Supports (LTSS)

Our panelists were: (1) **Dragana Ciric**, Executive Director of the Mental Disability Rights Initiative in Serbia; (2) **Dana Korinkova**, a lawyer in the Czech Republic working on behalf of QUIP; (3) **Hezzy Smith**, director of a supported decision making pilot project by CUNY and past leader of projects in Bangladesh and Mexico; (4) **Sharon Lewis**, Principal at Health Management Associates with many years experience in United States federal government programs for people with disabilities; and (5) **Ruthie Marie Beckwith**, Executive Director at TASH and clinical professional with expertise in treating people with significant disabilities.

The following were the major themes in Long Term Services and Supports:

Standards for how supported decision making and LTSS interact are different from country to country. In some countries there is neither a longstanding history of LTSS use nor a long history of institutionalization. In other countries, LTSS only exist in institutions and nowhere else. Circles of support (groups of people who can provide aid and LTSS in the community for a person with a disability and coordinate together, including supporters, doctors, landlords, etc.) are one idea that we felt had broad cross-country applicability.

The summit attendees proposed a record-keeping system showing what decisions a person with a disability has made already and how the person makes decisions. This record ensures that the capabilities of people with disabilities are not forgotten and that progress does not have to start from "square one" when service providers are changed.

Final Thoughts and Themes

Our Wrap-Up presentation was presented by **Barbara Brent**, Director of State Policy at the National Association of State Directors of Developmental Disability Services, and **Samantha Crane**, Director of Legal and Public Policy at the Autistic Self Advocacy Network.

Barbara Brent summarized the panels and discussions which took place at the summit, and offered two points: (1) people who are employed in the community are much more likely to be independent; and (2) every area we spoke about blended to a certain extent with every other area. We cannot afford to be experts in only one aspect of community integration. **Samantha Crane** summed up many points made at the summit by stating that guardianship can itself complicate removing people from institutions, and that our focus should be on changing how we look at the capacity of people with disabilities.

Conclusion

Our summit raised many concerns about supported decision making as a model. It also raised many new ideas about how supported decision making can help make people with disabilities more a part of the fabric of everyday life. We feel that the discussion is not yet over, but that the summit has provided us with a starting point.