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LEGAL CAPACITY: SUPPORTED DECISION MAKING AND BEYOND GUARDIANSHIP A NATIONAL ROUNDTABLE

INTRODUCTION

On October 30, 2012, 26 people converged in New York City for a Roundtable to begin a national conversation about the impact of the Convention on the Right of People With Disabilities ("CRPD") on the rights of persons with intellectual disabilities ("PWIDs") to make their own decisions. As the briefing paper they received described, the discussion was to explore concrete ways to move from a model of *substituted* decision making -- guardianship -- to one of *supported* decision making, consistent with the human right of legal capacity.

The invited participants represented experts and stakeholders from a variety of disciplines and organizations[1]: lawyers; physicians; educators; service providers; disability funders; siblings; parents; self advocates; attorneys from state policy and advocacy organizations, civil liberties and the judiciary; representatives from ARC and its state affiliates, and the National Guardianship Association[2]; and government attorneys from the Department of Justice and Department of Education. (A complete list of attendees is attached as Appendix A.) The Roundtable was convened by two Commissions of the American Bar Association ("ABA"), the Commission on Disability Rights ("CDR") and the Commission on Law and Aging ("COLA"), with support from the Agency on Intellectual and Developmental Disabilities

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[1] The briefing paper is available by contacting amy.allbright@americanbar.org.

[2] Attendees were drawn from major organizations but participated in their personal rather than official capacities.

("AIDD") within the United States Department of Health and Human Services. The Roundtable was made possible by financial assistance from AIDD, the New York Community Trust ("NYCT"), and the New York State Commission on Quality Care ("CQC").

SUMMARY

The Roundtable discussion was rich and wide-ranging, and does not easily lend itself to synthesis. As a consequence, an edited version of the entire proceedings comprises the major part of this report. There were, however, a number of major themes, as well as specific areas for further work and investigation, which are summarized below.

Kris Glen opened the Roundtable, greeting the participants and offering an overview of the planners' intentions and expectations. She gave a short history of guardianship laws, and then described the new lens of international human rights, which holds that all persons have legal capacity, and the right to make their own decisions. The notion of legal capacity, included in Article 12 of the CRPD, challenges the existing paradigm of substituted decision making for PWIDs and pushes us to move to a new legal and social framework of supported decision making. Describing the process by which previous guardianship reform took place, she noted the planners' idea of a similar national Symposium that could lead to standards necessary for legal reform. She noted, however, that as lawyers, she and the others from COLA and CDR had very little knowledge of how supported decision making works on the ground, or what resources are available or could be re-purposed. One purpose of the Roundtable was to bring together PWIDs, and those who work with them in a variety of ways, to start a conversation that might ultimately lead to the end of guardianship as we know it.

Sharon Lewis challenged the group to begin to understand the priorities – given both the challenges and the opportunities – necessary to pursue a new agenda in which the goal would be realization of the legal capacity of all PWIDs, including those with severe or profound communicative disabilities. She noted the changing landscape in which this conversation is taking place, with the increasing importance of families in the lives of PWIDs. At the same time that families provide opportunities, however, they also create challenges resulting from over-protectiveness; the dignity of risk is a difficult but critical conversation. Lewis also pointed to the emergence of a first generation of PWIDs who have grown up with the ADA, lived at home rather than in institutional settings, graduated from high school and even college.

As many other speakers would do throughout the day, Lewis noted the very different populations included on the general category of PWIDs, but suggested that, for the purpose of the Roundtable, participants focus on persons with developmental disabilities who are already covered by the autonomy-respecting provisions of the DD Act.

The main presentation of the morning was by Michael Bach. Intended to frame the day's discussions, Bach raised a number of issues and questions which elicited comment during the remainder of the meeting. For convenience, those subsequent conversations are briefly described here following each of his queries.

Bach began with the basic premise that Article 12 breaks the link between assumed levels of mental and communicative capacities (that is, understanding, appreciation, and the ability to communicate same) and legal capacity (the right to make one's choices and have them legally recognized). This, he pointed out, creates intellectual, philosophical and legal challenges; as to the philosophical challenges, illustratively he spoke about the concept of "personhood" that lies at the root of legal capacity.

Bach explained the functions of support, through which persons in a relationship of trust and knowledge can effectively convey or translate a PWID's will and preference to others, and distinguished support from the accommodations that third parties can and must make available. With appropriate support *and* accommodations, all people can make choices; the issue then becomes how to ensure that those choices – which are removed by guardianship – have legal and practical recognition in the world.

Bach described the legal capacity work he has been involved in in Canada and a number of countries around the world. He set out steps – and questions that need to be answered – in making the hoped-for transformation.

First, he asked, how to build a bridge between the existing guardianship regime and full supported decision making?

> This question was addressed throughout the day with a number of different suggestions, including making it easier for persons currently under guardianship to remove their guardians, to incorporating supported decision making as an alternative that must be exhausted before guardianship can be imposed. Missouri is engaged in a two year process, including monitoring, that should be studied. Current standards for guardians should emphasize independent decision making and the supports that may necessitate. The recommendations of the recent Guardianship Summit should be utilized to improve the relationship between guardians and PUGs.

Second, he asked, how would supporters be appointed, and what process or processes would be necessary to have them legally recognized?

> These issues, which had also been propounded by the framing paper, were the subject of some considerable discussion, through very little emerged in the way of specific recommendations. One group of participants, in an afternoon

> session, strongly suggested that the "imprimatur" necessary to reassure and protect third parties recognizing supporters should take place somewhere other than the judicial system. Significant concern was also expressed about possible conflicts of interest or undue influence, and how to determine whether "relationships of trust" were, in fact, "trustworthy."

A third question posed by Bach was where to fund the resources necessary for supported decision making, including resources to create networks of support and trust.

> Participants had several ideas, including training families; encouraging families to involve a network of supporters; using changes in Medicaid funding to support necessary training; and looking at those models that seem to be working in places where PWIDs are, for example, buying homes and having similar legal decisions recognized. The likely lack of any significant government financing of support was frequently commented on.

Bach also asked how to protect the integrity of the decision making process.

> This topic was the subject of an afternoon presentation by Erica Wood on balancing rights and protection, in which she, in turn, raised a number of questions that would need to be addressed in moving toward a system of supported decision making. These included standards and expectations for supporters; whether there should be a reporting system; whether supporters should be required to maintain records and if so, to whom they would be available; what kind of monitoring would be required; should monitoring differ for different kinds of decisions; and would it be mandatory or only responsive to problems. Other participants argued that the current system is rife with abuse, so this should not be a concern that gets in the way of a robust use and recognition of supporters.

Wood also raised a question put to the group by Bach: how should disputes among supporters, or potential supporters, or between supporters and the PWID (where, for example her/his intellectual disability is psycho-social, and an immediate choice is at odds with her/his whole life experience, and potentially dangerous.) This last potential conflict connected to Bach's caution that, as to all the issues he raised, the difficulty of solutions/answers is compounded by the different legal frameworks applicable to different populations of PWIDs, especially those with psycho-social disability or mental illness.

Bach then challenged the group to define its theory of change, and to be concrete as to its assumptions about how the process of transformation will actually happen. He saw as the necessary dimensions of such a theory: education, political mobilization and legal formation. Each of these dimensions was the subject of considerable discussion throughout the day.

Education

Bach spoke of the need for "multiple learnings," and group participants identified and expanded on a number of locations where such learnings might take place, as well as the groups that must be engaged. These include

> PWIDs: using the Special Ed system to teach decision making skills progressively from pre-K through transition; using the transition planning in IDEA to give content to the free, adequate public education guaranteed by statute.
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> Families: educating them about the multiple capacities of PWIDs, the need to create a circle of supporters, including age appropriate supporters, and to have such in place long before parents are no longer available; teaching them, especially parents and siblings, about alternatives to guardianship; create an organization like PFLAG to support parents in supported decision making.
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> Professionals and Others Who Intersect With PWIDs: Psychiatrists and psychologists, who do capacity assessment must lean that capacity is not binary and that legal capacity is not dependent on a particular level of cognitive ability; there should be judicial training about the abilities of PWIDs, about the human right of legal capacity, and about the alternatives to guardianship; people in the Special Ed system need professional development in teaching decision making, self-advocacy, and self-determination skills; health care professions, financial professionals, etc. need education about non-traditional ways that PWIDs communicate, and appropriate accommodations, including how choices are offered.
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> The Disability Community: Demonstrating the non-traditional ways PWIDs can communicate; finding commonalities with other people with disabilities; understanding the similarities and differences in the issues for people with developmental disabilities, older persons with diminishing cognition and persons with psycho-social disabilities.

Society at Large: Educate all children about human rights and about disability as a human condition; teach people how to be supporters and/or to provide circles of support.

Political Mobilitation

Bach made several specific recommendations.

Establishing leadership: Bach emphasized, and participants consistently reiterated the need for self-advocates to take the lead in any mobilization; People First should embrace this issue and "take it on the road"; the first generation of PWIDs who have grown up under the ADA and DD Act provides a pool for potential leaders; make connection with international efforts; develop leadership in multiple communities (bankers, judges, siblings, etc.) to create a broad societal leadership base then can move the project forward and create both a long term agenda and short-term steps; recognize and include race and class differences.

Identifying Priorities: Suggestions and comments throughout the day focused on identifying existing successful systems of supported decision making and/or creating pilot projects; doing and promoting research on supported decision making, and on funding incentives and disincentives; resisting attacks on *Olmstead*; thinking about strategic litigation.

Creating a Vision for Ourselves, Including Core Concepts: Sharon Lewis encouraged the group to "think big"; redefine apparently basic concepts – for example, consent is traditionally defined as involving capacity, information and voluntaries, but the CRPD removes "capacity;" flesh out the concept of "person centered planning;" begin to have the difficult conversation about "dignity of risk;" understand and incorporate a race and class analysis so as not to simply create new procedures for rich and middle class white people.

Developing Pilot Projects to Have Stories to Tell: Do structural, in-depth interviews where there are successful pilots; use pilots – and existing situations – to demonstrate the similarities to the use of accommodations necessary for inclusion of people with other disabilities (ramps; universal design, etc.) so that this does not seem so radical, or scary; collect stories on self-determination and decision making from self-advocates, family members and judges.

Developing Practical Tools for Professions to Understand and Assist in Supported Decision Making: Develop "human capital" in the Special Ed system, especially for high school teachers, include supported decision making in transition planning and trainers' materials.

Understanding This Is Not Going to Happen All at Once: lack of resources means we are not likely to have legal change as quickly – or comprehensively – as countries that have been working for years and have government support; use the human rights concept of progressive realization; do not get discouraged by the difficulties and obstacles, to achieve comprehensive, systemic change; be "strategically incremental."

Legal Framework

Bach noted that, although the change process will not necessarily be driven by legal reform, the theory of change must necessarily include *legal* recognition of supported decision making. As the discussions throughout the day made clear, the effort to create a new legal framework consistent with the right of legal capacity should proceed on a number of fronts.

> Federal efforts: Utilizing the changes in Medicaid funding to emphasize and facilitate supported decision making; getting DOE and HHS to instruct states that parents of children aging out of special education should not be told to seek guardianship, and, instead, should be informed of the many alternatives to guardianship; use IDEA to promote autonomy skills.
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> Building on Existing Systems: Make better use of powers of attorney, health care proxies, etc. and create forms in language understandable at a fifth grade level or lower; incorporate supported decision making as a necessary alternative that must be tried and fail before guardianship can be imposed; place limitations of some kinds of decisions guardians make; limit the number of cases professional guardians can take on; reform and ease procedures for people to get out from under guardianship. Use existing criminal system to punish – and prevent – abuse of PWIDs.
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> Role for the ABA: Look at and reform issues of capacity in Model Rules of Professional Responsibility in light of CRPD. Get ABA to support education on human rights beginning in primary school and require accountability; work with others toward generating recommendations and principles for establishing supported decision making.
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> Engage With International Efforts: Make connections with the work of Inclusion International and the Open Society Institute, as well as groups in Canada and the EU, sharing best practices and law reform proposals and strategies.
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> Developing Legislation: Need legal vehicles for recognizing supporters; developing a system for the appointment of supporters (preferably outside the judicial system), monitoring and dispute resolution; legislation must provide for protection from abuse and exploitation, consistent with CRPD, but fear should not trump rights; create the basis for independent human rights monitoring of the recognition of legal capacity in courts, financial institutions, etc.

While representative, the above summary is far from a complete list of the ideas and suggestions that were offered in response to Bach's challenges to the group. Significantly, however, he concluded that the real challenge, at this point, is not so much about technical solutions, or the mechanisms that need to be built, at local, state and national levels; rather, it is "about the process of learning that needs to be created and the leadership that must be built."

NEXT STEPS

Bach's prescription for learnings and leadership provide a good frame for much of the afternoon discussion, especially the last, somewhat truncated session (as the facilitator and others commented, there was *so much* more to say . . .) and for the work of the planners as they formulate "next steps."

Learnings

1. Research: Throughout the day there was discussion of research that needs to be done, commissioned and facilitated. This includes everything from how supported decision making is working on the ground, including evaluation of these systems, with Nina Kohn's work a good starting place,[3] to a study of the financial incentives and disincentives for supported decision making in current service funding. How is transition planning under IDEA promoting or ignoring the skills necessary to enhance decision making? What efforts are being made around the country to incorporate supported decision making in person centered planning? in guardianship proceedings, or strategies to avoid guardianship? What are the existing legal tools – powers of attorney, health care proxies, that foster and serve supported decision making and how and where are they being used effectively to avoid guardianship? What is the actual life experience of PUGs, and how does it differ from PWIDs who are not under guardianship?

2. Education: At the same time that existing programs, legal structures, etc. are evaluated, there needs to be broad based education about PWIDs, their capacities, the non-traditional ways in which they may communicate, and how, with the use of supports and accommodations, they can make choices that are entitled to legal recognition. PWIDs and self-advocates must be in the forefront of this process, which is not only about information and overcoming prejudice and stigma, but about "changing hearts and minds." "Experts by experience" who bring their voices and stories provide not only important information, but inspiration. Education must occur in, and be tailored to, different groups, including PWIDs and their families, judges and lawyers, health care professionals, including those doing capacity evaluations, persons in financial institutions, etc.; all the learnings/education should occur in the context of, and

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[3] Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN. STATE L. REV. 1113 (2013).

informed by, ongoing conversations, including best practices, at the local, national and international levels.

Building Leadership

1. In Multiple Communities: Bach encouraged building leadership in multiple communities – bankers, judges, educators, etc. as well as developing real solidarity with the larger disabilities movement in order to create a broad-based movement for change. Here, there must also be a serious conversation among the different groups of PWIDs (developmentally disabled, older and cognitively diminished, people with mental illness) with openness to the different interests and strategies they may bring. The "good people" who have worked, and are working to reform and improve guardianship should not be shut out. The issue of supported decision making needs to get on the agendas of many groups working with and around PWID issues. Participants could bring the conversation from the Roundtable back to their home organizations and affiliations.

2. Structure: With all that must be done, participants repeatedly noted the need both for a place or places to continue and build on the conversations at the Roundtable, and for a "center" where information could be gathered and disseminated, strategies formulated and implemented. While a number of subsequent Roundtables would be optimal, there does not appear to be funding or energy; engaging existing organizations, as, for example, the National Association of State DD Directors to spotlight the issue at their annual meetings might be a good alternative. The ABA and AIDD will continue to do what they can to continue the conversation, and, as a specific commitment, COLA agreed to create and maintain a listserv for participants and, potentially, other interested people.

The idea of a national Symposium is still very much alive, though now less oriented to generating recommendations for legal change (which seem, to most participants, to be premature) than to coming up with a set of general principles and commentary – similar, perhaps, to the Irish model (available at http://www.amnesty.ie/reports/essential-principles-irish-legal-capacity-law) which could be taken back to all the organizations and communities represented at the Symposium. Each group (including the lawyers) could use the general principles in their own work. Funding is obviously an issue, and there may be need for grant proposals for further meetings, for pilot projects, and for research. A "central place" is necessary for this as well as for the steps (including commissioning briefing papers, using the ABA model) necessary for any national symposium. Here, it is useful also to build on Irfan Hassan's observation that funders are more interested in work that brings about broad policy change than in new or better forms of service provision.

CONCLUSION

The planners agreed to take the transcript of the meeting, the notes taken by the facilitator and the afternoon group leaders, and to create a report – this document – which would be supplied to the funders and which would be used to strategize, propose, seek funding and buy-in for the next steps toward "Supported Decision Making and Beyond Guardianship."

PROCEEDINGS

Opening Remarks

The Roundtable began with a general introduction and review of the schedule and ground rules by facilitator Deborah Spitalnick. She also thanked all those who made it possible, including the staff of the New York County Surrogates' Court, which hosted the proceedings. Spitalnick emphasized that the focus of the discussion was to move *beyond* guardianship, rather than describing and reiterating the perceived failures of the existing guardianship regime. She then introduced one of the organizers of the Roundtable, Judge Kristin Booth Glen.[4]

1) Kristin Booth Glen

Glen explained that, in addition to a history of advocacy and scholarship on adult guardianship, she had served for the past seven years in the court with jurisdiction over guardianship of persons with intellectual disabilities. She briefly described the legal status of

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[4] Glen is a member of CDR, and was the primary author of the briefing paper distributed prior to the Roundtable.

guardianship –the process by which the state removes an individual's right and ability to make some or all choices about his/her life and/or property (guardianship of the person and/or property) and grants that power to another individual or institution, the guardian.[5] She also spoke of the history of guardianship laws and reforms: from draconian laws in which the imposition of guardianship stripped the person under guardianship ("PUG"), usually called the "ward,"[6] of all decision making, and as well, most or all civil rights. As a result of reforms in the 1980's, led in large part by CDR and COLA, states moved to statutes[7] whose stated purpose was to promote autonomy, which were based on functional assessments of capacity rather than on a diagnosis, which favored or mandated limited, tailored guardianships over the previous model of plenary guardianships, and which provided a plethora of procedural protections before guardianship could be imposed, as well as substantial periodic reporting and review thereafter. Glen noted that while such laws, as written – constituted a significant improvement, the reality was that in most cases, in most courts, hearings were perfunctory and plenary guardianships continued to be the norm.[8]

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[5] Terminology varies from state to state, with guardian the most common term, but also, as in California, including conservator.

[6] In accordance with "people first" language, *see*, *e.g.*, Matthew Hennessey, *People-First Language*, FIRST THINGS/ON THE SQUARE (June 7, 2013), the term PUG will be utilized, despite the unfortunate acronym, rather than "ward," which suggests that the person is completely subsumed by her/his legal status.

[7] Most states have a single statute that covers guardianship for all populations, while five have statutes specifically dealing with persons with intellectual disabilities, in addition to their adult guardianship statutes. *See* American Bar Association, Commission on Law and Aging, State Adult Guardianship Legislation: Directions of Reform—2011, *available at* http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_gship_reform_12.authcheckdam.pdf .

[8] She noted the lack of hard information on the numbers of PUGs in the country, variously estimated at between one and three million. This lack of statistical and empirical data surfaced throughout the day's discussion.

While there has been some modest movement toward reforming guardianship laws for PWIDs, especially given the broad spectrum of ability and disability covered by the definition of intellectual disability, a major impetus now has come from the CRPD, which was signed by the United States in 2009, and where ratification remains pending in the United States Senate. The CRPD, and particularly Article 12,[9] changed the lens through which we must view guardianship from one of civil rights to one of human rights. The latter depends not on rights conferred by the state, but rather rights which exist by virtue of being born a human being; such rights are universal, indivisible, inter-related and intra-dependent.[10] Article 12 not only recognizes the right to make one's own decisions, and to have those decisions legally recognized, but also to have the supports necessary to permit an individual to exercise her/his right.

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[9] **Article 12 - Equal recognition before the law**

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

[10] That is, the rights enumerated in the CRPD must be understood as working simultaneously. For example, the right to live in the community, enunciated in Article 19, is interdependent with the Article 12 right to have one's decision legally recognized.

Glen noted that this shift necessarily signaled the end of a system of substituted decision making for PWIDs, as recent decisions of the Committee monitoring the CRPD have held in reviewing – and condemning – guardianship laws in a number of countries that have ratified the CRPD. The issue, therefore, is not how well intentioned a guardian may be, or how much he or she may invoke the "best interests" of the PUG, but the fact that, under guardianship, it is the guardian, not the PUG, who is making choices; this is incompatible with the PUG's right to legal capacity. If current guardianship laws cannot withstand analysis and/or challenge under a human rights model, how do we move to a model of true support decision making?

Glen observed that although lawyers were asking these questions, they were largely ignorant of the ways in which supported decision making actually occurs on the ground, and about what resources are currently available or could be re-purposed to meet the obligation to provide supports. She stressed the need to bring the experience and expertise of the disability community – service providers, advocates, educators, family member, and, of course, PWIDs – to the table to begin to chart a path to "beyond guardianship," and she acknowledged the invaluable assistance of AIDD in identifying the Roundtable participants as just such representatives.

A major issue, Glen observed, was that of strategy, and she recounted the successful efforts of COLA and CDR in earlier guardianship reform. The model they created involved a multi-disciplinary national symposium that generated a series of recommendations. Those recommendations, in turn, were adopted by the ABA, and then employed in reform efforts in the 50 states. The Roundtable was envisioned as a necessary precursor to a similar process which was to include a national symposium, targeted for the fall of 2013 or spring of 2014. Glen also noted that similar efforts to "move beyond guardianship" were ongoing around the world, with particular emphasis on Canada and the European Union, so that there is a substantial body of legal, philosophical, policy, and, to a much lesser degree, empirical work on supported decision making to guide us as we move forward.

Glen reflected that any immediate or short term abolition of existing guardianship laws was highly unlikely, as was the likelihood that government would provide the resources necessary for the support mandated by Article 12. What she suggested, as one possible and more modest first step, was developing ways to move people out of the guardianship regime, by identifying the reasons for which individuals and families sought guardianship, generally because of interactions with third parties, such as banks and other financial institutions, health care providers, service providers and those providing government benefits. She proposed that, using the experience of the ways in which PWIDs can make decisions with the aid of supporters, the task could be to imagine and create ways to have those decisions recognized by third parties who could be legally protected when they did so.[11]

2) Sharon Lewis

The next speaker Spitalnick introduced was Sharon Lewis, Commissioner of AIDD. Lewis began by echoing the opportunities created by the CRPD, but cautioning that its enforceability as law "for lots of different political, policy and legal issues" is far away. She also noted the very different populations covered by the term PWID, including aging persons with cognitive decline, who pose very different issues. For this conversation, she proposed focusing on persons with developmental disabilities, and on the vision and provisions of the DD Act which sees "disability as a national part of the human experience that does not diminish the right

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[11] That is, a bank that recognized a PWID's supported decision to withdraw funds would not be subject to subsequent legal challenge, or a doctor who acted on a PWID's medical choice would be legally protected from a charge of battery or malpractice.

of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, not only if they can." That right is also the right to full participation in, and contribution to their communities, "through full integration and inclusion in the economic, political, social, cultural and educational mainstream." The right is not something conferred by others; it is inherent, despite the difficulty of implementation. And, she noted, issues of race and class make implementation even more difficult.

Lewis expressed her belief that, despite the broad spectrum of disabilities, with many persons able to self advocate, but many also, because of communication and other issues, unable to do so, *every* individual, given the opportunity and support, is able to express her/his preferences and volition. This belief, she stressed, needs to be "a given" in the day's conversation.

Lewis noted two contextual areas that require recognition, investigation and inclusion in any strategy for moving beyond guardianship. The first is the increasing role of the family, as institutional care becomes a model of the past. She offered these statistics: of approximately 5 million PWIDs in the country, around 20% are in the formal service system, receiving SSI and Medicaid. 60% of those are living with their families, in supported living or independently, as opposed to segregated or congregate institutions, and this percentage will only increase over time as states reorganize their delivery systems, and families express their preferences.

As families become more important, it is necessary not only to rethink the delivery of services, but also the question of who needs to be in the room when we talk about supported decision making. The centrality of family raises issues of conflict of interest, and over-protectiveness, with the latter, often coming from well-intentioned family members, sometimes presenting a significant obstacle to the to the right of PWID's to make their own decisions.

The second context issue, related to families' understandable desire to protect their children/siblings with developmental disabilities, is that of the dignity of risk. Lewis described this as "the scariest conversation for families," acknowledging the tension it creates, but reaffirming that, as a matter of constitutional and civil rights, safety should not/cannot trump freedom, choice and self-determination.

Finally, Lewis charged the participants to "think big," to focus on the ideal goal, while exploring the "points along the way that might get us there." She stated that

> Our goal here today is to begin to understand enough of what the priorities might be, in terms of both the challenges and the opportunities to pursue a new agenda, and what information . . . potential research, writing, thinking . . . we need to be able to pursue that agenda "

The agenda, she concluded might result in a symposium, in the model previously used by the ABA Commissions, focused on PWIDs and supported decision making.

3) Michael Bach

Following these introductory remarks, Michael Bach, Managing Director of the Institute for Research and Development on Inclusion in Society, Executive Vice President of the Canadian Association for Community Living, and a leading proponent of the human rights approach to supported decision making, provided an overview of the work on that issue that has been done in Canada over the past several decades. Significantly, that work grew out of the 1991 founding convention of the self-advocacy group, People First of Canada, where the very first resolution was to abolish guardianship laws. Bach began by stressing the importance of self-advocates, the principle of "nothing about us without us," and the need for solidarity with the broader disability movement.

A. The CRPD

The work involved thinking about comprehensive systemic change, and toward that end, the Canadian movement focused heavily on the CRPD, and on the inclusion of Article 12 in order to obtain the commitment to, and recognition of legal capacity in international law. Bach summarized the main points of Article 12 as follows:

First, quoting the convention, "people with disabilities have a right to legal capacity on an equal basis in all aspects of life, without discrimination on the basis of disability." This is not a presumption; it cannot be taken away. There are no loopholes. The question is recognizing "the different ways in which people might exercise that capacity."

The second point, in Paragraph 3, is the issue of access to necessary supports, which is one of the main subjects of the Roundtable. According to the Convention, all such measures must respect the "will and preferences" of the person.

Third, is the definition of legal capacity, which is *not* "having the mental capacity to understand and appreciate all the consequences of a decision." Instead, it is the power to control, and to exercise control in legal transactions. That power is something that is respected and recognized, it is not attributed on the basis of specified intellectual characteristics. What the CRPD does is break, absolutely, any link between assumed levels of mental and communication capacities and the recognition of legal capacity. Bach noted that this break "poses – an intellectual, philosophical, legal challenge" that must be confronted.

As a practical matter, legal capacity is the power to create, nullify or extinguish legal relationships in areas like healthcare, financial and property decisions and personal life decisions such as where a person lives, works, with whom s/he is in relationships, how she moves through her day. If legal capacity is not recognized by relevant others, guardianship is the "remedy" by which such relationships are managed, and, in this respect, guardianship removes an individual's legal personhood.

Various articles in the CRPD address rights – like the right to live independently in the community, which cannot be enjoyed without legal capacity. That is, an individual must have the ability to sign a lease for an apartment, or to go to a bank and open a bank account in order to actualize her Art. 19 right. The right of legal capacity is the basis that allows an individual to engage in the practical activities that make up and define the shape of her life.

Guardianship violates the right to legal capacity by applying criteria in order for decision making to be recognized – the ability to independently understand and appreciate the information necessary to make a decision. In the absence of such abilities, legal personhood is removed, guardianship imposed, and another person is vested with the power to make and have decisions respected.

B. Thinking About Personhood

Bach noted an irony here, because the principle of informed consent, and the ways in which it is assessed, grew out of the abuse of PWIDs in the healthcare system and the attempt to protect them by the threat of a charge of battery against doctors who overstepped boundaries, and engaged in treatment that was not duly authorized. But, he argued, this is not the only way to think about and respect personhood. Just because a person cannot express her will and preference to others generally does not mean that she cannot express choice to at least one person – a relative, a friend – who understands and can assist in communicating the will or preference. The law, to date, has said that is not enough, Bach argued that

> "what supported decision making calls upon us to do is to make that gesture, that volition, that expression of intention . . . the basis on which [a person's] right to legal capacity can be found."

Returning to the more philosophical construct of personhood that underlies these issues, Bach spoke about "personal identity," that is, the fact that an individual can be recognized as a person through time. This is a basis of contract law – the belief that a promise a person makes today, to pay back a loan, for example – is something s/he will carry out in the future, because s/he is the same person. To the extent that legal capacity has been understood to require a person to communicate her story in a way which permits her identity to be seen over time, PWID's can be excluded from our understanding of personhood, and thus from legal capacity. If, however, a PWID has people – supporters – around her who know and can construct her story over time, to make sense of apparent discontinuities, this should – *must* – be recognized as the foundation on which legal capacity can rest. Ultimately, Bach said, the CRPD calls upon us to expand, and broaden the reach of our collective understanding of what it means to be a person.

As an example, he pointed to a woman named Rebecca who has significant intellectual and communicative disabilities, but who is a member of a dance group that performs concerts and even has a video. There are contracts for these endeavors, and they are in Rebecca's own name. While she may not fully understand the nature and consequences of the terms of those contracts, she has expressed her desire to engage in these activities, and to be part of the dance group, which makes her happy. This is her volition in the world, expressed in decisions about the contract, that are made by her support group. Her ability to enter into the contract – her personhood – as well as the legal responsibilities that attach, are accomplished by her support group which is empowered by her to execute contracts and agreements that are driven by her intention and wish.

C. Creating Legally Binding Agreements

Bach continued: the legal challenge that this Roundtable has been convened to address is how we attach legally binding agreements to people like Rebecca. How can their identities and stories be constructed to permit them to, for example, sign a lease, without meeting the existing criteria for "capacity," that is, understanding and appreciating all the consequences?

Here, Bach suggested that participants think about the equation between decision making abilities and legal capacities. While, prior to the CRPD, an individual's ability to understand, appreciate and communicate constituted the requirement for legal capacity, the CRPD recognized that people have differing abilities: in Rebecca's case, her *ability* is to express herself in a way that only a few can understand. If you add to her *ability* the *supports* of her friends in communicating, and the *accommodations* given by the landlord, or the doctor, or the bank, you have accomplished and established her legal capacity. That is, the unique mix of a PWID's particular abilities, the supports she needs and the accommodations provided by third parties create "decision making capability sufficient to ground and express [her] legal capacity through various transactions and agreements."

D. Supported Decision Making

Supported decision making, therefore, is a kind of status and a set of relationships that is being worked out in various jurisdictions around the world. It is comprised of a number of different steps.

First, it involves a PWID's legal right to have certain people recognized as her supporters. Obviously, not everyone can simply step in and say she is going to be a supporter. Here, it is important to note that while the Roundtable's focus is on PWIDs, these legal issues involve other populations, including older persons who are progressively losing cognitive ability. The legal processes we create have to take them into account, and, in the case of older persons, there are frequently conflicts among family members, particularly around the control and disposition of financial assets. In such situations, where potential supporters disagree about what the person wants to do with her property, how do we decide who gets appointed and recognized as a supporter?

To be a supporter, he suggested, one must be in a demonstrated, trusting relationship of personal knowledge and commitment with the PWID. Supporters are a group of trusted others who assist in expressing the PWID's will and preference to others and help in weaving her story in a coherent way that will make sense to a third party, like a doctor.[12] There must be certain legally imposed requirements and duties, as well as the legal obligation of third parties to recognize the supporter. This legal obligation is a consequence of the state's recognition of the role that supporters play in assisting the PWID in making decisions, and, as well, the duties of third parties in the community to accommodate her.

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[12] Here, Bach distinguished between what the supporters do – take the PWID's expressions and gestures and make them sensible to the world, representing her because of, and by their personal knowledge of her – and what the doctor may do provide plain language, or even a communication interpreter. The former is support, the latter an accommodation.

E. “Making One’s Way” in the World

Given this construct, how, Bach asked, does the PWID make her way into the community, open a bank account, take money out of that account? This scenario is a real problem in Canada, where the banks are happy to take the PWID’s money, but, when she comes to withdraw funds, question her capacity to enter into that transaction.

Making one’s way in the community can happen in several ways. The person without disabilities simply goes to the bank, the doctor, etc., and exercises her legal capacity which is duly recognized. Or, as Bach described, she can do so through supported decision making – it is still the PWID who is “making her way” – albeit with supports and accommodations. Or, as a third possibility, there can be representative decision making. This is when the PWID appoints a person or persons to make decisions for her at some point in the future. While that person may be making substituted decisions, it is the PWID who gave her/him the power, and did so as an expression of self-determination.

There is a fourth category of PWIDs for whom “making one’s way” or exercising legal capacity is most problematic. This includes persons who have been institutionalized for a long period, and persons who are completely isolated and who have no friends or people who know them well and can play an interpretive role. These are persons for whom there are no supporters. There are also persons with certain psycho social disabilities, like schizophrenia, who may be expressing will and preference, and need support in doing so, but who make it very difficult for supporters. On one hand, the person’s will and preference at a given moment may be at odds with that person’s life over time and might result in serious or even life threatening consequences. On the other, she is expressing her will and preference, and we might argue that should be honored, regardless. This is a place where the notion of personhood becomes extremely problematic. Do we best protect legal personhood by requesting some authority to make a substituted decision to protect the situation? This is an issue that we need to struggle with, and we need to do it as a community. We need to find some kind of "regulated process" to engage in this struggle, rather than to create a blanket solution for all difficult cases.

F. Necessary Steps to a New Framework

All of this, Bach explained, requires us to think about the steps we need to take to build a legal framework, including what kind of bridge can be built between the existing system of guardianship and supported decision making. One question is what windows exist in current guardianship law that could be exploited in this movement, both by judges and advocates.

Another necessary step is how decision-making supporters get appointed. When someone lacks the "capacity" ordinarily required to execute a power of attorney, what alternative forums or processes exist? One possibility is the model of representation agreements, as in British Columbia, where the threshold of mental and communicative capacity is lowered, and where the test is whether the PWID can express a relationship of trust with the supporters who have come forward. What should the process be? Simply going to a lawyer getting it signed? The experience in Canada now is that to make this a real guarantee of legal capacity, it will be necessary to have some kind of imprimatur from a public authority that would approve the appointment. This, in turn, raises the question of who or what this public authority is, and how it makes its determination.

There are more questions to be answered. Where do the resources come from, or how do we create them, in order to assure PWIDs of networks of trust? What is the community capacity to support individuals, and to build support networks, or how might we create it? Who provides communication in supports, and how do we protect the integrity of the decision-making process?

As Bach acknowledged, the issue of resources is huge. Where does a network go when it is struggling over how to interpret what a PWID wants, and what could that mean? Where do third parties go when they want to understand what an appropriate accommodation might entail? And if there are cases where we believe facilitated decision making is necessary – as, for example, for the person in a full blown schizophrenic episode – where does that decision get made, and how do we ensure that it is both limited and takes into account an appropriate understanding for determining the person's decision-making capacity at that moment?

There are more questions: What is the process for resolving disputes – where, for example, there are two potential supporters, both in a trusting relationship, who have different views of what the PWID wants and what should be done. What process do we need to prevent abuse and/or to create a place for someone to report suspected abuse by a supporter? And are there decisions that are so important and critical to physical and/or mental integrity – like sterilization – that we should not allow supporters to make them without some assurance to a court or some other public authority that the PWID has some understanding of the issue and the choice.

G. Some Specific Recommendations

All these issues, Bach noted, are compounded by the different legal frameworks that apply to PWIDs, persons with psycho-social disabilities, and older persons losing cognitive capacity. Bach encouraged a wider conversation among these various groups that might also build some solidarity for the legal and political challenges that will necessarily arise. In countries in which he has been working, including Zambia, Bulgaria and Columbia, bringing these different communities together has led to a rich exchange of understanding.

Bach concluded with some specific recommendations: establishing leadership; identifying priorities; creating a vision for ourselves, including core concepts, that can also lead to some legislative proposals; developing pilot projects to have stories to tell about how supported decision making works on the ground; developing practical tools for professionals to understand and assist in supported decision making; and finally, understanding that this is not going to happen all at once, and committing to working progressively to realize the goal of legal capacity for all people. He proposed that the group be "strategically incremental," developing leadership in multiple communities, including self-advocates, and other professionals to create a "broad, societal kind of leadership base that can move [the project] forward and create a long term agenda in the short term steps."

FIRST GROUP SESSION

Spitalnick asked participants to introduce themselves briefly, indicating how they are connected to the topic, and laying out either their vision, or questions or challenges. The comments that ensued fell roughly into five areas: education, language/conceptualization, strategies, working within/reforming existing guardianship, and research. The comments are brief summarized below.

Education

There was consensus that we need to work on new strategies for educating a variety of populations as well as improving education for PWIDs.

1. Educating All Children

Leigh Ann C. Kingsbury, Innovations in Leadership and Supports, Inc., noted the importance of the Universal Declaration of Human Rights to a basic understanding and appreciation of the human rights model, arguing that it should be taught throughout the K-12 curriculum, and suggesting ways of insuring that it is – including a human rights focus in No Child Left Behind, and in the National Assessment of Educational Progress. Beth Haroules expanded on this suggesting that all children be educated not only about human rights, but about disability and disability rights. Kids need to understand that disability is a part of life, that people with disabilities are, first and foremost, *people*, and that they have the ability to choose, to communicate although sometimes in non-traditional ways, and to have needs and desires like everyone else.

2. Educating PWIDs

There was a strong consensus that special education needs to be improved, particularly with respect to teaching PWIDs decision making skills from the earliest grades, continuously through their transition out of the Special Ed system. While the language in IDEA on transition planning is excellent, and could be utilized in this effort, state implementation, generally speaking is poor to terrible. Arlene Kanter noted that transition planning often contains a presumption of the need for guardianship and encourages parents to assume that guardianship is the likely next step. Can IDEA be used to promote and require that children be taught autonomy skills? Kanter noted that self-advocacy skills should be taught to all kids, but especially to PWIDs, where such instruction should begin early and continue throughout the curriculum.

3. Educating the Disability Community

Ari Ne'eman, Autistic Self-Advocacy Network, noted the importance of "buy-in" from "our own community," including educating the community that PWIDs with severe communicative disabilities, are able to express their views, albeit in non-traditional ways. Katie Arnold, Sibling Leadership Network (Chicago), noted the importance of siblings, especially in the transition from parental involvement, and suggested beginning earlier in teaching the families of

PWIDs about their capacity for self-determination and the ways in which that capacity can be developed and nurtured.

4. Educating Others

There was general agreement on the enormous importance of educating the community at large, and especially those whose positions cause them to interact with PWIDs about their abilities, means of communication, appropriate accommodations, and human right to legal capacity. Amy Allbright asked how do we educate the third parties, like doctors, bankers, judges to understand the capabilities of PWIDs? Sheryl White-Scott, MD, FACP, Community Health Services at AHRC, reminded us of the importance of bringing marginalized groups – poor people, people of color, language challenged persons – into the conversation and to educate them about the need for autonomy and self determination for PWIDs.

Language/Conceptualization

Both in thinking about education and about strategies, participants raised issues of our use of language and of the necessity to redefine apparently basic concepts to facilitate the move to supported decision making.

Ruth Luckasson, University of New Mexico, noted that, while the traditional definition of consent includes capacity, information and voluntariness, the CRPD removes capacity from the equation. Information and voluntariness are both susceptible to supports, so this is a useful way of thinking about legal capacity as the right to give consent and have it recognized. Leigh Ann Kingsbury suggested the importance of thinking about the definition of "responsibility" generally as including 1) accountability for consequences; 2) understanding how things work/rationality; 3) freedom and 4) **[REPORTER DID NOT GET THIS]**, accordingly, understanding "decision-making" should be understood as determining on the basis of what is possible; choosing among alternatives; basing the choice on your own **[MISSING]** and discovering and investing new options.

Paul Kietzman, New York State ARC, encouraged us to think more critically about the concept of "dignity of risk" which, for providers, is often utilized only when someone is injured. He asked, "Where is the dignity on assuming a risk that a person does not understand?"

Leigh Ann Kingsbury spoke of the importance of fleshing out the concept of person centered planning, focusing on centrality of the statement "I am a person, I am a human being" and asking how that guides the process. Dr. Sheryl While-Scott pointed out the tension, in any discussion of "rights," between the rights of PWIDs, and the rights of their families in a supporting role.

Working Within/Reforming Guardianship

As part of an incremental strategy to move from the current paradigm to supported decision making, many participants saw ways to bring change to the existing guardianship system that could move in that direction; they also noted some of the challenges connected to such an approach.

Susan Eckles, Missouri Protection and Advocacy Services, explained that Missouri is currently engaged in guardianship reform, working with stakeholders toward a facilitated decision making model. There is a two-year project, the Guardianship Project, sponsored by the Missouri Planning Council on Developmental Disabilities that involves collaboration between Missouri People First, the Institute for Human Development at UNKC (IHD), and Missouri P&A. The agencies involved have two priorities. First, they will host a series of trainings which focus on less-restrictive alternatives to guardianship. Second, they will assist clients with developmental disabilities in challenging current guardianship arrangements that needlessly restrict their rights.

Arlene Kanter asked how, if we attempt to move formally/legally to supported decision making, we prevent facilitated decision making as a last resort – which is really substituted decision making, from becoming the default position, just as plenary guardianship, also the supposed last resort, is the default in the current system?

Jane Gildersleeve, National Guardianship Association, suggested making documents used in guardianship more compatible with Person Centered Planning, as well as having documents and standards of practice more clearly reflective of a level of independent decision making that requires support for its exercise.

Nina Kohn reminded the participants to judge systems not by their aspirations, but rather by their outcomes.

Ari Ne'eman, Autistic Self Advocacy Network, proposed a number of changes to the existing system: making it easier to get out from under guardianship; placing a heavy burden on the proponent of continuing guardianship, regulating "professional guardians," including limiting the number of cases they can handle and requiring that they meet with and interact with their "wards" (and enforcing that obligation); and creating an absolute prohibition on guardians approving certain medical procedures, most obviously sterilization and abortion or carrying a pregnancy to term if the ward expresses a preference contrary to the guardian.

Both Ari and Liz Weintraub, Association of University Centers on Disabilities, expressed concern that there were no persons currently under guardianship at the table – their presence is important to overcoming perceptions that they are unable to communicate their preferences. Arlene Kanter asked participants to think about the similarities and differences between groups of persons who have had guardians, or been subject to guardianship over time – the elderly, PWIDs, people with mental illness. How do these differences result in, or drive practical policy responses?

Strategies

1. Differing Populations

The issue of differences and similarities between groups subject to guardianship figured strongly in comments about strategies.

Beth Haroules, New York Civil Liberties Union, noted the policy differences that may flow from the fact that PWIDs may need expensive and high intensity services over a lifetime, as opposed to more periodic interventions for persons with mental illness, or later and more time limited services for older persons. She also noted the special problems and challenges arising from the intersection of race, poverty and disability, both because poor and minority families are far less able to advocate for their children with intellectual disabilities, and, because of the stigma attached to disability, those families often do not get connected to services. She referenced the Willowbrook plaintiffs, who she represents, who were totally abandoned by their families.

Nina Kohn pointed out that interventions that have an upside for one population might have a downside for a different population – and that, in some instances, their needs might be directly contradicting.

Erica Wood reiterated the need to deal with the common abilities and differences of the aging and developmentally disabled communities, noting also the need to create a bridge to the “very good people” who are working on reform of guardianship for older and incapacitated adults.

2. Leadership

While Michael Bach urged us to develop leaders in all the relevant communities, he also emphasized that self-advocates have to be at the forefront of any successful movement, as they have been in Canada.

Liz Weintraub pointed to herself as an example of different kinds of decision making. She makes some decisions on her own and, as to others, has chosen particular individuals to make them for her.

Sharon Lewis pointed out that there is now a first generation of PWIDs who have grown up with the ADA, gone to high school and college, whose existence – and leadership – can change perceptions about intellectual disability that challenge the basic assumptions of guardianship.

3. Examples and Pilot Projects

There was a very broad conversation on the need to create and/or identify successful examples of supported decision-making.

Roger Bearden, New York State Commission on Quality of Care and Advocacy for Persons with Disabilities, noted that change generally comes out of crisis, and that, at least for most people, there is no sense of crisis here. An alternative, however, could be small pilot projects that can demonstrate that supported decision making is neither scary nor utopian, that it is not dissimilar to other ways in which we support persons with other kinds of disabilities (mobility, blindness) in living and exercising their choice (ramps, universal design bathrooms, braille signage).

Molly Burgdorf, AIDD, stressed the need to identify models that are working in terms of putting supported decision making into law, policy and community.

Dohn Hoyle, ARC of Michigan, suggested that there are already tools “out there,” and reminded participants that the more you respect people’s choices, the more confident and outgoing they will be about expressing them.

4. Challenges

Liz Weintraub pointed out that existing laws are state based, so the question is whether it is necessary to work on an individual state basis, and whether it is possible to develop some sort of national consensus.

Kris Glen noted the difference between the situation in the United States and that in places like Canada and the European Union and its member nations where there is both government involvement in moving to supported decision-making and considerable resources made available for the work of transition. She argued that the lack of cooperation and/or resources should not be an excuse for not moving forward, even if that movement is incremental.

Sharon Lewis saw challenges in the forthcoming changes in the way Medicaid funds service delivery systems. She also expressed concern about threats to *Olmstead*, which she characterized as the backbone to all our rights claims to residential services.

5. Funding

Joanna Pierson, ARC of Frederick County, asked why, if there are federal funds for behavioral plans, shouldn’t the government fund decision-making plans, and communication plans? Irfan Hassan spoke of the importance, for funders, of a project that delivers real policy change, not just a good service model.

6. Possible Strategies Involving the ABA

Beth Haroules suggested looking at the Code of Professional Responsibility as it relates to disability, nothing that current provisions speak to "protective measures" for allegedly incapacitated persons, but make no mention of supported decision-making.

Leigh Ann Kingsbury proposed that the ABA support education on human rights beginning in primary school and insist on accountability with respect to such educational requirements.

Research

[This fell out; I am going back to find the comments & put them in here]

CONCLUSION OF THE MORNING SESSION

1. Theory of Change

Michael Bach concluded the morning by asking the critical questions: What is your theory of change? What are the assumptions about how a change process is actually going to happen?

He proceeded to summarize a number of the dimensions of that process, from education of PWIDs to the legal framework. Because of the limited resources available, he focused on the need for multiple learning processes – in education systems, families, the legal profession, third parties and institutions that interact with PWIDs like health care professionals and banks. The change process is not going to be driven entirely by legal reform but requires piloting, on the ground, to demonstrate that supported decision making really can work.

There needs to be a political mobilization, because although there are many people for whom existence of guardianship is a real crisis, there does not seem to be a general, shared sense of crisis, or any political urgency. One very serious consideration here is whether we should only be talking about, and advocating for PWIDs, or whether we need to have a movement across the sectors that are affected by guardianship. For Canadians, because of its huge geographical area and relatively small population, bringing the various groups together has been important, but here in the United States, it will need to be the subject of some very strategic discussions.

Then, Bach noted, it is also critical to think about who should be at the table to have these conversations, to formulate strategy, and to exercise leadership. The morning discussion had included suggestions on this topic, but Bach added his own experience drawn from many conferences and forums: that the conversation should start with "experts by experience" who bring their voices and their stories, and provide inspiration as well as important information. As they were, and are in Canada, self advocates must be at the table. Just as they were instrumental in closing institutions, they have an enormous role to play in ensuring that de-institutionalization does not simply result in a different system in which PWIDs are denied the right to make choices.

With respect to the "third parties," Bach drew on his experience dealing with bankers in Canada, and the difficulties and challenges they face, even if they want to "do the right thing," especially where people with profound intellectual disabilities are involved. Seeing this as a basic civil rights issue, Bach argued that when we think about the leadership issue in a theory of change, we need also to include leaders in the various professions – doctors, bankers, etc., who believe in this, and who will help the rest of us figure out how to make it work.

On the topic of "multiple strategies," Erica Wood intervened to note that even when there are leaders in the "third party" groups who see the issue as one of basic civil rights, the conversation inevitably turns to the hardest cases, and it is important that we think critically about them. She observed that we need to think about the role, if any, of strategic litigation. Finally, she raised the issue of independent human rights monitoring that would include monitoring what is occurring in places like courts or banks, from a human rights perspective.

2. Three Related Conversations

Bach responded that the conversation has to be, simultaneously, at a state, national and international level. While it is about the kind of mechanisms we want to build at each of these levels, the challenge now is not so much about technical solutions as it is about the process of learning that needs to be created, and the leadership that must be built.

On how we can engage on an international level: Bach noted the efforts of Inclusion International and the Open Society Foundation in convening and sponsoring forums for bringing people together around the world. Shortly after the CRPD was passed, a number of people came together and posited the idea of establishing principles and guidelines that they imagined everyone would then abide by. At this point, he said, there was general laughter. Recognizing the impossibility of that early enthusiasm, Bach reported that there is now, instead, recognition that change is going to occur differently on a country by country basis, because the change strategy is so complex, and because small-scale change will occur differently in different locales. While OSI is focusing on developing countries, it is critical that there be some central group working on these issues in the United States, and that there be actual United States examples of successful supported decision making. Creating such a group will pose its own problems, as any core group organized around PWIDs will have to negotiate how to engage with other groups, including persons with psycho-social disabilities. Once, however, there is a central group, it should definitely participate in the international conversation, sharing best practices, taking home ideas that can be used in local pilot projects and laws reform initiatives.

Bach concluded the morning by wishing the participants luck, and hoping that the conversation, including others on an international level with home he works, will continue.

AFTERNOON SESSION

The afternoon season began with Spitalnick describing the process that would be employed, understanding that it might not be possible to get through the entire agenda that had been designed for the Roundtable. The first task was a quick "brainstorming session" in which people worked in pairs, and then reported back to the group, on the topic of how to strengthen supported decision making, what the elements are, what needs to happen. Here, again, the responses are grouped by the general topics.

Brainstorming Session

Education

1. In the Special Ed Realm

There should be better professional development, including supported decision making, for people in the Special Ed system.

It is important to do capacity building, especially for high school teachers.

Human rights should be taught beginning in grade school.

Children must be taught the skills they need to make decisions from an early age; best practices as to how to do this should be shared.

2. Education of Third Parties

It is important to educate the professionals who do capacity evaluation that capacity is not binary, and that we need a continuum of capacities for different decision points. There should be capacity building and training for professionals, not just that people *make* choices in alternative ways, but how choices are *offered*.

Self-advocates should be used to educate professionals (judges, lawyers, bankers, educators).

People need to be educated that there are many non-traditional ways to express opinions and make choices.

Work with younger families to teach them that there are better options to guardianship.

Working Within/Reforming the Current Guardianship System

Get supported decision making into the conversation about "least restrictive alternative."

Chip away at the existing system by improving the relationship between guardian and ward using the resolutions from the Third National Guardianship Summit.

Federal Actions

In the pending CMS regulations, supported decision making should be included in some way.

HHS and DOE should work together to change the belief that guardianship is the first option when Special Ed students reach 18 or so that parents do not get a letter telling them to seek guardianship.

Research

There is a need to gather information on the actual lives and conditions of PWIDs under guardianship, and those who are not, and assess the differences.

What are the points that cause people, usually parents, to seek guardianship?

Gather information about teaching self-determination and supported decision making in education from early on through transition planning into adulthood.

We need to collect stories on self determination and supported decision making from self-advocates, family members, and judges.

Support Systems/Supporters

We need to clarify the terms that describe and identify "supporters."

Parents should be encouraged early on to create support circles that will outlive them.

In situations where there are no natural supports available for PWIDs, consider a model like the Consumer Advisory Board that is used for the Willowbrook plaintiffs.

Strategies

Building social capital is the key to promoting supported decision making.

We should build on the existing models of advance directives and health care proxies, noting both that the forms necessary should be written at a lower educational level (in New York, now, at a 5th grade level) and requiring a lesser degree of "capacity" than powers of attorney.

Use technology – apps, etc. – much of which is already available both to help in supported decision making and in doing outreach.

People First should be engaged and encouraged to take this issue "on the road."

It is important to remember the range of PWIDs whose rights we are talking about and be careful that we do not just create a new, expensive process that works for rich white people.

What are the resources available to assist in supported decision making and building networks of support in all the diverse settings – urban, rural, etc. – in which it needs to occur? Faith based institutions: volunteer organizations?

Small Group Session

Following the brainstorming session, Spitalnick divided the participants into groups, each of which had a pre-assigned facilitator, to explore ways to support and empower PWIDs to exercise their legal capacity and to make their own decisions, including existing resources and other mechanisms, ideas from other places, decision-making models, non-judicial models. The discussion here was to move "from the person outward, to systems, considerations and recommendations." At the conclusion of the group meetings, the facilitators reported back to all participants.

1. Legal Strategies

One focus was on possible legal strategies. Beginning with an understanding that guardianship is a matter of state law, one group looked to possible constitutional or legislative "hooks" based on a discrimination analysis to promote national change. A national focus is optimal because without national standards/requirements, people seeking guardianship will be able to jurisdiction shop. National legislation based on the spending power would appear to be a better "hook" than the 11th Amendment. Any federal legislative change, however, would be part of a long term strategy.

Existing federal legislation, like the ADA, is not especially useful here because it is sliced up based on remedies. One place that can tie guardianship and supported decision making together is the Medicaid/Services system where Guidances might be used to tie funding to requirements like quality assurance and person centered planning, but it is important to give this potential real teeth. Health care reform can provide opportunities, both to encourage looking at people's lives holistically, and to insert supported decision making into the conversation, using it as a lever to get on the national agenda.

Finally, on the legal front, it may be useful or necessary to have litigation over whether PWIDs have the ability to exercise a power of attorney or other advance directive, including using arguments based on accommodations where supported decision making is involved. Here, there is also the legislative example of representation agreements in some Canadian provinces where a lesser level of functional capacity is required. This whole issue requires considerations of "functional assessment" – what function does a person need to enter into an agreement? And, if we are thinking about legislation, we need to consider what the entry points are where the determination of capacity has to be made – what imprimatur will satisfy third parties that there is accountability.

2. Working in the Existing Guardianship System

The group affirmed that existing guardianship as incompatible with Article 12 of the CRPD and criticized any notion of building a "better" guardianship law as a deprivation of legal capacity. On the other hand, in a strategy of "progressive realization," it is important to build on the principle that guardianship must be the last alternative, available only after everything else has been attempted. "Least restrictive alternatives" requires consideration of existing resources such as trusts, powers of attorney, and proxies. The group felt that it will take time to educate the public and the disability community about legal capacity and non-discrimination; in the meanwhile the law should, at the least, insist on an evidence-based finding that a guardianship is actually necessary and, as well, should enforce an obligation on guardians to visit and interact with their wards.

Another group proposed that, given existing guardianship systems, we should, at the same time, try to insert supported decision making into those regimes and continue with reforms, such as the recommendations from the recent Guardianship Summit, encouraging due process, including the right to be present, and to counsel, so as not to abandon all those who are now under guardianship.

Sharon Lewis cautioned that we should not assume that guardianship is permanent, but rather a changing dynamic so it is necessary to build in a process of reassessment and review taking into account what we have heard about how hard it is to get out of guardianship. That review must, of necessity, consider the alternatives, whether a supported decision making team, or a particular supporter, a health care proxy, etc.

She also stressed that because decision making supports change constantly, any construct that we move toward, whether the education system, or person centered planning or in changes in the Medicaid system must include periodic review as a means of recognizing and honoring persons holistically, and also to guard against abuse or neglect.

3. Education

The group returned to the issue of education that had arisen throughout the day, noting particularly the importance of teachers who often give the incorrect legal advice that if parents do not get guardianship when their child reaches 18, they will no longer be able to participate in the child's education/IEP. We should view correcting this, possibly through state regulations, or a policy letter from DOE, as the front door – a way of preventing guardianship at the earliest point. Schools should put a premium on teaching decision making skills, not only to students, but also to parents, who may need help in seeing their children as "able." "Transition for all" would be both a guiding principle and a basis for litigation on equal protection grounds.

Knowledgeable parents are absolutely critical to the effort. In addition to correcting misinformation from the schools, Parent Training Centers (authorized in Part D of the Individuals with Disabilities Education Act (IDEA) and funded by the U. S. Department of Education, Office of Special Education Programs) should be training on guardianship, strongly communicating that there are alternatives to guardianship, and then identifying best practices. As part of this effort, information about supported decision making should be included in Association for Persons with Severe Handicaps' (TASH) trainer toolkit. A model for good training might be that which Dohn Hoyle is offering in Anaheim on December 1 **[GET MATERIALS]**.

Another group noted that, while it is important to educate and work with parents, it could also be helpful to create an organization to support them in this transition, like the parents' organization that grew up around LGBT rights, Parents, Families, and Friends of Gays and Lesbians (PFLAG). Education on supported decision making should include a dialogue with the health care professionals who do capacity evaluations, and targeted judicial education. It might be possible, with the re-authorization of IDEA, to get a pilot program to teach self-advocacy and decision making skills. We need to publicize the whole range of steps that can be utilized creatively to use media, including blogs, to increase awareness about the principles of supported decision making, and legal capacity as a human right.

4. Steps Toward a Symposium

The topic of collecting existing resources as well as identifying necessary research was also addressed. As a first step, it seems critical to have some central place where information can be accumulated, and the complicated conversations necessary to move forward can occur. The model of a national symposium seems attractive, with a mission to develop principles and recommendations for standards. Once these have been formulated, they can be taken to the states, to relevant organizations and stakeholders. It is important both to get buy-in from the entire disability community, and also to speak with a single voice – or, at least, with a single vocabulary. Principles and recommendations would also be useful in getting supported decision making on the conference agendas for doctors, lawyers, judges, etc.

There are many tasks before such a symposium can happen. We need to develop a list of existing studies and/or research and collect information from, *inter alia*, National Institute on Disability and Rehabilitation Research (NIDRR) and its grantees, University Centers **[[EXPLAIN WHO THESE ARE]**. We need to look at principles that have already been developed – both from the recent Guardianship Summit in the United States, and from the work of others promoting legal capacity around the world. We should compile existing materials as well as practices – on, *e.g.*, curriculum development, coaching, training – shared information as well as shared learning – all toward the end of building capacity.

It is difficult to find materials that take a stand against guardianship, so it would be useful to develop some sort of authoritative document that could be easily referenced. This could be a product of the symposium, or, perhaps, created as part of the run-op. Kris Glen's article is one possible resource.

At the same time, we need to think about funding, both for the information collection and research identified as necessary, and then for an actual Symposium. In planning the Symposium, it is critical to make it *really* representative. By getting everyone to the table we are more likely to come away with something people can live with, and make use of in developing policy, regulations, etc. Optimally, the Symposium would result in a set of guiding principles that could be utilized in various ways. As the Roundtable framing paper proposed, and the experience of the two commissions demonstrates, ABA endorsement would be a powerful tool, but a set of principles could also be presented to other organizations for approval, and as well, perhaps to individuals through a sign-on campaign. And, of course, we must be certain that any set of principles is itself accessible, and or plain language so that it can be understandable by all people.

5. Interim Steps and Shorter Term Strategies

In addition to a national Symposium, and actions necessary to bring that about, the group thought about a larger national effort moving toward supported decision making. We need both a long term plan and a list of steps to take in the meantime. For one, we should look at the financial incentives and disincentives to supported decision making, both nationally and by state. For example, in some states, courts get funded based on the number of cases they handle, so this is a disincentive. We should also lay out the options of alternatives to guardianship and identify the tools that are being used around the country – proxies, powers of attorney, etc. Because these alternatives may sometimes fail, when they come up against third parties like banks or hospitals, we might want to concentrate on state and funding agencies where there is more room to educate and compel compliance. If we can create – or identify – some other device or agreement we should find agencies that accept them, but with the understanding that despite that device/agreement, the PWID may still be in need of, and entitled to, services.

State agencies can be our allies in this effort; the National Association of State Agencies on Developmental Disabilities is frustrated with guardianship laws that counter the integration imperative. They are looking for ways to make guardianship less of a burden for people to live lives they want, so we need to use them to embrace the message of supported decision making, and to create options and models, as well as, eventually to adopt the standards that come out of a Symposium or other national effort. This engagement with state agencies is critical because even if it were possible to set up and impose some requirement of supported decision making nationally, there is no guarantee that it would be utilized on the ground.

6. Identifying Existing Models Creating A Research Agenda

Finally, as has been repeated again and again, it is absolutely necessary to identify systems that are already working – where, for example, PWIDs are buying homes without a guardian, using some combination of durable powers of attorney, interpreters, social security rep payees, etc. – and the banks are willing to accept their decisions **[WHERE IS THIS? NOTES SAY "IT'S HAPPENING"]** and to tell those stories.

As Roger Bearden pointed out, because culture change is necessary, we have to change people's perceptions and assumptions about PWIDs through such examples. We need to look for ways to build on existing structures that are familiar, even if not always used as well or extensively as they might be; the movement to supported decision making necessarily benefits from connecting it to the legitimacy of existing systems.

We need to build a research agenda that identifies natural supports and circles of support, and that could include doing some very structured interviews in settings where supported decision making is actually occurring.

7. Dealing With "Entry Points" for PWIDs

Another group looked more specifically at the ways, short of guardianship, to deal with those "entry points" where PWID's choices and decisions come up against third parties like the education system, doctors, state disability agencies, SSI, etc., and the latter's need for accountability. This effort would require excellent person centered planning tools, and the use of healthcare proxies, powers of attorney, representation agreements, etc. that could be given a stamp of approval, or imprimatur of legitimacy that third parties could rely on outside the judicial process. One aspect of the necessary acceptance by third parties would be a legal presumption of "universal capacity power." **[EXPLAIN]**

A speaker then raised the issue of "scoping" and points of contact for different populations whose legal capacity should be recognized through the use of supported decision making. If the scope is confined to those who are qualified for services available to those with disabilities, there is already a lot of information since the agencies collect significant amounts of data because of Medicaid and other regulations. For that population, it is possible to build supported decision making structures into the services they are receiving. But other populations, specifically older persons who are losing capacity or experiencing diminished ability to make decisions, may not be connected to any formal systems, there is no similar framework to build on. And, finally, if there is a consensus to move all of this outside the judicial system, there are even more questions about accountability, who and how is gathering the necessary data, and under what auspices.

Liz Weintraub reiterated the importance of PWIDs being in the forefront of any change strategy, while another speaker encouraged participants to share any good models or practices already in place, or to point to models that might be successfully “tweaked” toward supported decision making.

As facilitator, Spitalnick summarized and noted that the considerations for going forward, both for planning a symposium and otherwise, include issues about how information will be collected, what structure or structures should be employed, what mechanisms, and where such information should be located.

Balancing Rights and Protection

The penultimate session consisted of a brief presentation by Erica Wood, followed by a somewhat truncated (Hurricane Sandy was approaching) discussion.

Wood began by explaining that her special concern about this issue derives from concerns about financial exploitation of older incapacitated persons and a current push by the United States Department on Aging on the need for protection against such abuse.

She noted that the CRPD itself specifically provides for protection, both in Article 12 (“appropriate and effective safeguards to prevent abuse;” all measures taken to ensure legal capacity must be “free of undue influence and conflict of interest”) and Article 16 (states parties must protect persons with disabilities “from exploitation, violence and abuse.”)

On one hand, supported decision making depends on trust, and trust, like a power of attorney, can open the door to abuse. On the other hand, the goal of supported decision making should not be "squashed" by the threat of coercion and malfeasance. Balance is what is needed; the question is where the tipping point lies between rights and protection. In the current guardianship system there is, ostensibly, court oversight, but unfortunately this is more aspirational than real.

Canadian proposals utilize the concept of "monitors," and this may provide a useful starting point.

As we think about the issue of protection, we need to ask – and answer – a number of questions.

1. What are the standards and/or expectations for supporters?
2. What would be the system for complaints and dispute resolution? Is mediation one possibility?
3. Should there be a mandatory reporting system for supporters?
4. Should supporters/representatives be required to keep records, and, if so, should they be made available and to whom?
5. Do we want a registration system with periodic review, or monitoring only a check when there are problems?
6. Do we want different kinds of monitoring for different kinds of decisions?
7. How do we guard against the often subtle problem of undue influence or conflict of interest?

In response to these questions, Dohn Hoyle argued that it is a myth to think that we currently have protection in the guardianship system; in his state, Michigan, both public and private guardians have engaged in bad financial dealings, and the likelihood is that there are even worse abuses in the context of personal care. We should acknowledge that guardianship makes PWIDs even more vulnerable when we are balancing rights and protection.[13]

In the lively discussion that ensued, the following points were made:

- The vast majority of PWIDs are not under guardianship, so that is where we should start. People will make well-intentioned mistakes; but for more serious abuse and neglect we already have systems in place; perhaps they need tweaking, but this should be the starting place.

- There are already serious problems with the systems in place to report abuse and neglect in institutions, they simply are not working. How can we expect to extend systems to a much more diffuse, non-institutionalized world?

- Working off the existing system, the real crises are in the quality of community services that are available. We need to ask what people really need to meet their needs and to help them reach their goals. Instead of just trying to avoid bad things, as the Medicaid and state systems are changing, let us look more to the outcomes we want, rather than those we want to prevent.

- In terms of the existing systems that deal with abuse and neglect, we need to empower PWIDs to have real access to the justice system – this is the flip side of "protection." There is a good model in Israel which has a unique program for training law enforcement professionals and advocates for persons with communication disabilities to enable them to testify, and to overcome questions about whether PWIDs are "credible" witnesses.

- As we evolve in these initiatives, like training, we should have some independent entity to evaluate them.

- Any move to take cases of abuse and exploitation of PWIDs out of the criminal justice system is mistaken; just as the system has developed ways to provide kids and victims of sexual assault the means to participate effectively, training for prosecutors and others, including the use of communicative devices, should be employed to allow PWIDs full and equal access for the vindication of their rights.

- In terms of prevention, it is important to broaden the circle of supporters, including age appropriate supporters. The more people who are involved as in person centered planning, the better the protection. (The imperative to "spread the net widely" was emphasized by several speakers.)

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[13] Responding to Dohn Hoyle, Ari Ne'eman urged that more time should be spent on current guardianship abuse, including conflict of interest, especially involving service providers as guardians. He also noted that professional guardians have more cases than they can reasonably and responsibly handle.

- Protection and rights do not necessarily have to be balanced against each other; they can be mutually supportive. Crimes are crimes, and should be punished as such, but instead of an after-the-fact response we need a system to prevent abuse, undue influence, etc. from the outset. This involves some important distinctions: trust relationships vs. good outcomes; loved ones vs. people we treat well; exposure to risk vs. the dignity of risk. And, it is important to remember, proposed solutions to a bad model are not always an improvement.

- We need a less formalized, legalistic model; instead we should rely on a group of people who love and care about the PWID, and change the language we use from "best interest to best respect."

NEXT STEPS

Leaving many unanswered questions, Spitalnick asked the group to focus on next steps, having already come up with a number of strategies, questions, etc.

Sharon Lewis noted that the Roundtable process had begun with an assumption that the goal was a national Symposium to be held within a year, tasked with generating a set of recommendations and principles that could be taken to the ABA for approval, and used to make legislative change. Michael Bach's question about theory of change makes that approach somewhat more problematic. What we certainly have is AIDD's commitment, and, as well, the ABA's, to continue the dialogue, with "a goal at the end that may yet be undefined."

A participant responded that we are not yet ready for a definitive national Symposium, and that it would probably take one or more Roundtables as well as some more defined models and, optimally, pilot projects. If the only goal is a legal strategy, perhaps the ABA model is appropriate, but if we are looking for more, we are just "not there" yet.

Kris Glen followed, suggesting that the *idea* of a symposium, as opposed to the proposed *product*, seems very much alive, especially since there are so many people who should be part of it, but who are not present at the Roundtable. Acknowledging that there are disagreements on some areas, she reiterated, as the starting point, that all people have legal capacity and the right to be recognized as such. While that is not going to happen tomorrow, we need to use the human rights model of progressive realization to get there, without knowing precise what the steps necessary to do so may be. The next step is to get everyone, or as many diverse people as possible to the table, having collected and shared information, to come up with some general principles that we could take back to the various constituencies we represent. We could then utilize those principles in a strategic planning kind of way – as the lens through which we construct our next moves. Short of a Symposium, it is hard to think of another place or process by which this could happen.

We are certainly not ready to have a Symposium such as that which we originally envisioned, to come up with a set of legislative proposals within the next year. The ABA does, however, already have some policy on this, as it supported the CRPD. It is just another step – which we can try to accomplish – to get a more explicit statement recognizing the right to legal capacity in Article 12, the ways in which the current guardianship system is inimical to that right, and the need for progressive realization by (eventually) doing away with guardianship. Such a resolution might be very useful to many of the participants, especially because the ABA is seen as a generally conservative organization.

Glen suggested that it might then be possible to move to a Symposium which could be used to generate general principles with commentary, the model used by Irish advocates. Their work was attached to the briefing paper. The result might or might not be similar to what they generated, but there would be a broad constituency and the ability to utilize such principles in implementation strategies. To do this, however, we need a lot more information – a call that we have been hearing all day – so it would be very helpful to identify with some level of specificity some of the issues we believe need to be worked on before we move to a larger gathering or symposium.

For example, people suggested that we look at funding incentives and disincentives – it would be terrific if someone could do a state by state analysis, since there are apparently so many differences among the states. There are probably 15 more areas that we have already identified as needing more research and/or work.

While it would be optimal to have one or more additional Roundtables, as a realistic matter, there does not seem to be the funding or the energy; it would also be wonderful if there could be regional meetings, or if the different organizations that are formally and informally represented here could hold their own meetings as precursors to something bigger and national in scope. Again, though, speaking practically, the original Symposium model seems the most possible, even though the goal of such a Symposium has shifted pretty significantly as a result of the discussions here.

Erica Wood then described the process the ABA has used in the past as a successful model. First, you must identify and bring together a diverse, multi-disciplinary group. Almost certainly everyone will not agree with everyone else, which is a good thing on increasing awareness, but which also results in very difficult discussions. The way we have found to best deal with this is to prepare participants in advance with very detailed and precise issue briefs, which everyone is expected to read in advance of the meeting.

At the meeting/symposium, participants are divided into three iterated working groups. First, they are asked to describe the present situation – here it would be where are we now with PWIDs making decisions, for the good and the bad. The second group topic is visionary: what do we want to happen? What would it look like? Finally, the groups work on the action steps needed to get there. All of this is reported by the groups to a plenary, which adopts recommendations and/or principles.

Representatives from different groups who have participated then bring the result back to their own organizations and particular policy making bodies. It is not just a legal model for the ABA – it is a whole range of organizations – here it might be bankers, social workers, healthcare providers – the sky's the limit.

Alison Barkoff, DOJ Civil Rights Division, pointed out that if a Symposium is to be planned for a year or so hence, there is a huge amount of groundwork to be done, including real grass-roots education, but that we also need to be opportunistic as issues and opportunities arise in the meanwhile as, for example, new Medicaid regulations and waivers. It is critical to get this issue on people's radar, identifying people who are talking about these general issues in a different way, and making alliances. We need to put these issues out in a simple to understand way – and action around the CRPD present a great opportunity to do so.

Katie Arnold suggested that one opportunity is a sibling survival guide that she is in the process of writing. The guide already contains a section on guardianship and alternatives, so this will be a really good place to "plant the seeds" and get conversations going.

The issue of a necessary research agenda was raised again and Erica Wood requested a laundry list of topics that might be used for the briefing papers that could inform the next step of the conversation. One potential issue, raised by Ari, was the options available to persons currently under guardianship to remove the guardians. Nina Kohn indicated that she had laid out some initial research questions in her article; it is important for people to have something to cite, about the importance of these issues, especially if they are seeking grants or support to do more work in the field. Arlene Kanter gave a laundry list of possible topics. **[CITE]** **[I have e-mailed Arlene who promises to get a list to me]**

There was also substantial discussion on the issue of who should be at the table for any subsequent gatherings, with a strong emphasis on more self advocates, on persons actually under guardianship, as well as the necessity to include family activists concerned with end of life issues **[Not dead yet? Diane Coleman & Stephen Drake?]**, and state directors of developmental disability services. Leigh Ann Kingsbury suggested _______, a systems theorist who offers multiple works [??] on how to build person centered system services.

Amy Allbright, on behalf of CDR, indicated that it would be helpful if participants sent their ideas to a central place – and volunteered to be the repository, as well as to create a listserv for participants.

CONCLUSION

Spitalnick indicated that we had, unfortunately, come to the end of the day, having had a very full discussion, and, as well, with much more still to say. She stated her hopes that those who had brought the Roundtable to fruition, especially the ABA, AIDD, and the Community Trust would take responsibility for thinking through next steps.

Sharon Lewis concluded the session by thanking everyone for their participation and hard work, and assured the group that she and other planners would take the transcript of the meeting, the suggestions and thoughts she expected others to have following the meeting – which she encouraged everyone to share through the listserv reconvene, figure out how to push that group out further, and define the next steps.

Erica Wood thanked Deborah Spitalnick for her skill and willingness to take on this difficult assignment; she in turned thanked Kris Glen and the staff at the Surrogate's Court, and Amy Allbright and the ABA, and the meeting concluded.

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