Supported Decision-Making, Human Rights, and Legal Capacity for People with I/DD

NRC-SDM Symposium, June 11, 2019

Kristin Booth Glen

University Professor and Dean Emerita

CUNY School of Law

SDMNY Project Director

Where does SDM come from?

- Our common experience of how everyone makes decisions
- The human right of every person to make her/his own decisions regardless of disability

Where Do Human Rights Come from?

- Consequence of WW II and the Holocaust
- Creation of the United Nations (1946)
- Universal Declaration of Human Rights (1948)(signed by all nations; has moral weight); announcing and recognizing the rights to which all persons are entitled by virtue of being born human;
- Subsequent legally binding treaties (e.g. International Covenant on Civil and Political Rights or ICCPR; International Covenant on Economic, Social & Cultural Rights or ICESCR; etc.); principles and rights become legal obligations of nations that ratify
- Treaties for 5 “Vulnerable Groups”

.

Vulnerable Groups Requiring Additional Conventions

- Racial and Ethnic Minorities (Convention on the Elimination of All Forms of Racial Discrimination or CERD, 1965)
- Children (Convention on the Rights of the Child, 1990)
- Women (Convention to Eliminate All Forms of Discrimination Against Women or CEDAW, 1979)
- People with Disabilities (Convention on the Rights of Persons with Disabilities or CRPD, 2008)
- Older Persons (in process)

Human Rights are

- Inalienable
- Indivisible
- Inter-related
- Intra-connected
- Premised in Equality, Non-Discrimination and Dignity
- Positive (economic, social & cultural rights) as well as Negative (civil rights)

Dignity

- Whereas recognition of the inherent dignity and the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world
  - Universal Declaration of Human Rights (UDHR), Preface

Dignity, cont'd

- UN Convention on the Rights of Persons with Disabilities (CRPD), Art. 3 General Principles:
  - (3) Respect for inherent dignity, individual autonomy including the *freedom to make one's own choices*…

Purpose of the CRPD

- To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by PWDs
- PWDs include those who have long term physical, mental, intellectual or sensory impairment in which interaction with various barriers may hinder their full and effective participation in society on an equal basis with others

A Convention of Many “Firsts”

- First human rights treaty of the 21st Century
- Fastest negotiated HR treaty in UN history
- Most active participation of civil society: PWDs “at the table” & “Nothing about us without us”
- First HR convention with an explicit social development dimension

UN Convention on the Rights of Persons with Disabilities (CRPD) Article 12

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.

Legal Capacity Defined

- “legal capacity includes the ‘capacity to act’ intended as the capacity [capability?] and **power to engage in a particular undertaking or transaction** to maintain a particular status or relationship with another individual, and more in general to create, modify or extinguish legal relationships”
  - Background paper on Legal Capacity—Office of the High Commissioner for Human Rights

Legal capacity, the "epiphenomenon"

- "It provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe—a web of mutual rights and obligations voluntarily entered into with others. So it allows for an expression of the will in the lifeworld…."

Legal capacity, the "epiphenomenon" cont'd

- "Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions. It does so primarily through contract law. Michael Bach is entirely right to focus on issues like opening and maintaining a bank account, going to the doctor without hassle, buying and selling in the open market, renting accommodations, etc. This is how we positively express our freedom. This is how we can see legal capacity as a sword to forge our own way."

  - Gerard Quinn

CRPD Rights Requiring Legal Capacity (Interdependent, Intra-related)

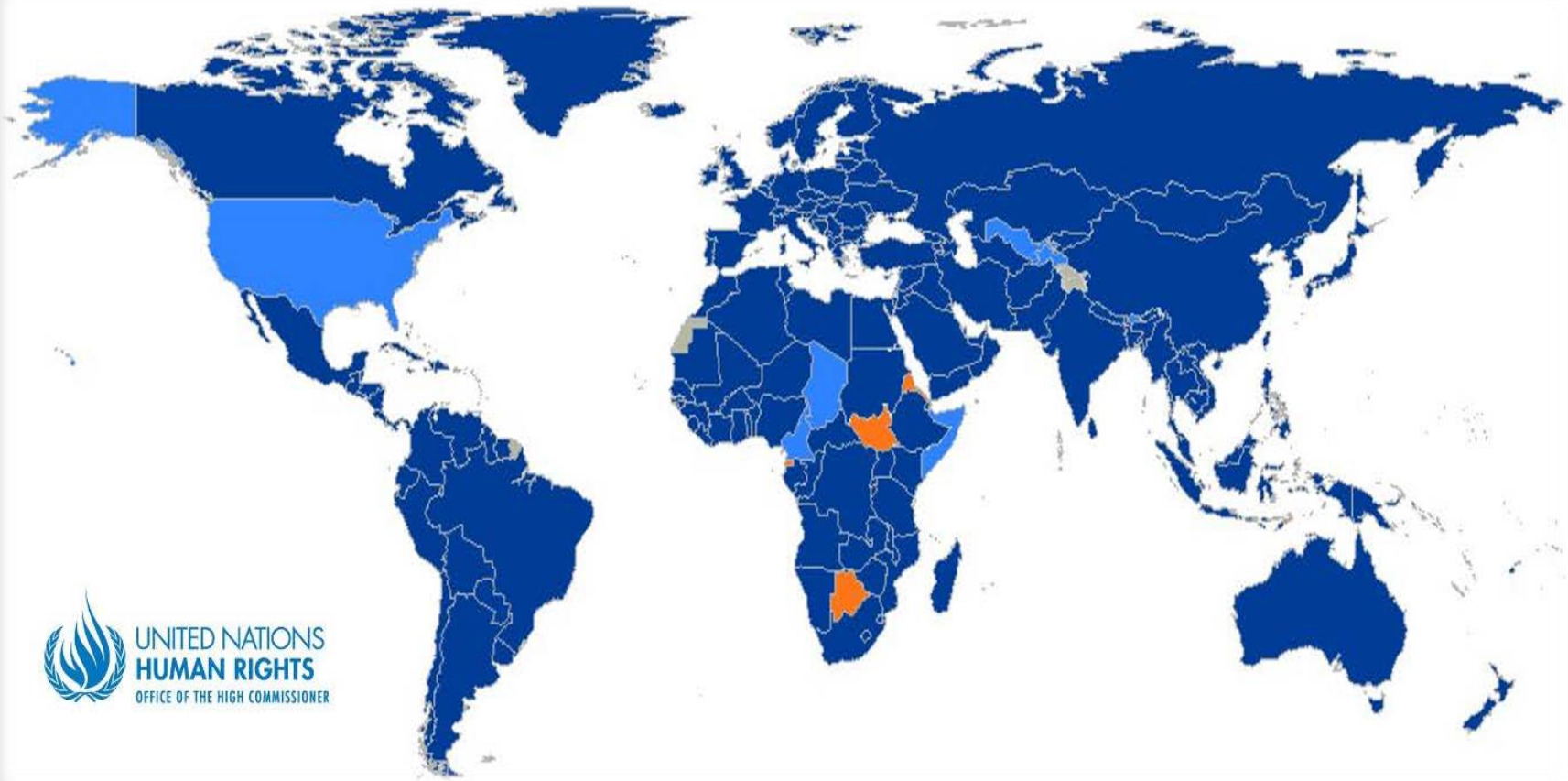
- Health Care Decisions: arts. 15, 25, 26
- Financial/Property Decisions: arts. 12(5) & 28
- Personal Life Decisions: arts. 13, 14, 15, 18, 19, 20, 21, 25, 26, 27, 28, 29, 30
  - (where to live, relationships, participation, access, employment, mobility and supports)

SDM from a human rights perspective

- SDM is the ***means*** to the ***end*** of legal capacity for people with I/DD, cognitive and psychosocial disabilities, so that they may make their own decisions and have those decisions legally recognized “on an equal basis with all others”

Convention on the Rights of Persons with Disabilities

Last updated: 23 May 2019

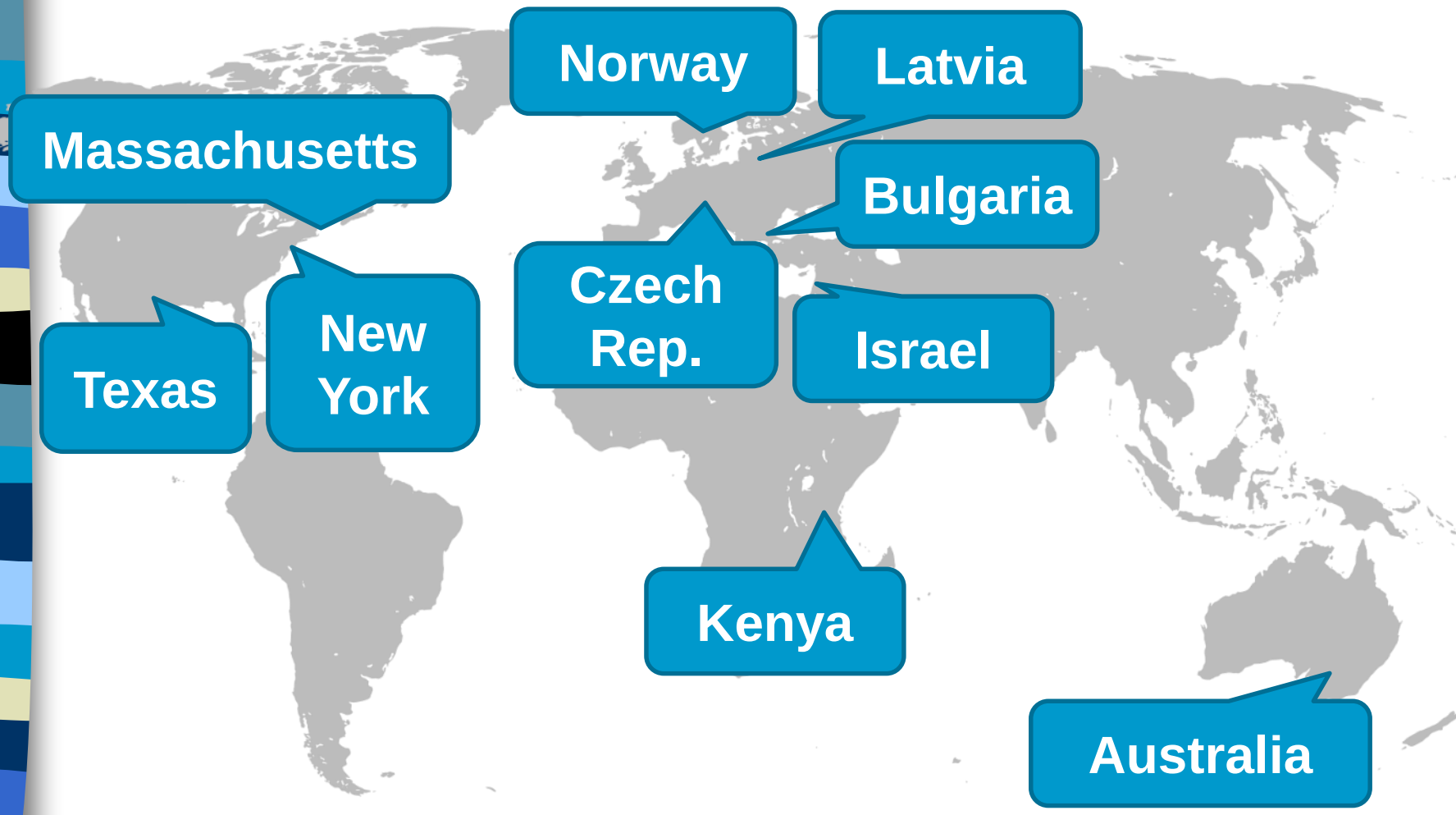


State Party (178) **Signatory (11)** **No Action (9)**

How is SDM being implemented around the world?

- Legislation to limit or abolish guardianship, recognize and promote SDM (Ireland, Israel, Peru as different models)
- Pilot projects to demonstrate that SDM can empower and protect persons with I/DD

Pilot Projects



Characteristics of Pilot Projects

- All involve, and are focused on the ***process*** of SDM, not just an agreement
- All use facilitators, some paid (Bulgaria) some NGO staff (Czech Republic, Kenya), some provider agency staff (Massachusetts, Australia) some volunteers (SDMNY, Australia)
- Supporters may be chosen from people already in the person's life (Mass., SDMNY, Kenya, etc.) from a community of volunteers (Bulgaria) or paid (Israel)
- All take time, most commonly, six months to a year
- All include people with I/DD and some include persons with psychosocial disabilities as well (Bulgaria, Czech Republic, Kenya)
- All are funded as pilots, whether by government, foundations or a combination
- Little to no experience with persons with high levels of support needs

What have we learned from the pilots?

- For people with I/DD, SDM really works! (the good news)
- Every pilot is different in relatively minor but specific ways, often related to funding
- The judiciary is a hard nut to crack
- Process-based pilots don’t always lead to legislation (but Israel?)
- Governments haven’t yet committed to major expansion (or at least to paying for it)

Where are we in the US?

- Increasing interest in SDM from stakeholders, especially as “an alternative to guardianship”
- Understanding that SDM can happen in many different ways: informally, through a structured facilitation process, or through statutory recognition
- Laws recognizing SDM in six states (Texas, Delaware, Wisconsin, Alaska, Indiana and Nevada, and DC)
- Slow, but some progress in judicial recognition of SDM
- A wide variety of practices for utilizing SDM

Challenges going forward

- Expanding current models to people with higher needs for support
- Developing and piloting different models for other populations (older persons with cognitive disabilities dementia; persons with psychosocial disabilities)
  - appropriate kinds of support for one group will not be the same for others
- Continuing to experiment and share best practices, and finding resources to do so
- “Normalizing” SDM (Alaska?) and overcoming stigma and discrimination against people with I/DD
- Building political support
- Scaling up successful models (involves funding, legislation, and caution)

The Need for Legislation

- Statues recognizing SDM and SDMAs, requiring third party acceptance and granting relief from liability where acceptance is in good faith, providing safeguards that the Decision Maker's will and preference are primary
- Abolishing or severely limiting guardianship
- Attention to the many other laws, decisions and regulations that limit legal capacity on the basis of disability (voting, marriage, service as a juror or witness, wills and trusts, etc.)

Michael Bach's Lessons in the Change Process

- Remember: it can't happen all at once-keep vision in focus
- Be strategically "incremental"
- Show how it works in practice
- Develop leadership for change
- Create long term agenda with short-term steps

Why use a human rights lens/model?

- It's a more affirmative way to look at the world and our work
- It makes clear that SDM is rights-based, with an entitlement to support—not welfare-based, or expedient
- It provides a lodestar as we move into applying SDM to other groups—older persons with cognitive impairment, dementia, etc.; people with psychosocial disabilities
- It connects us with a vast network of work going on around the world from which we can learn
- Human rights have been successfully used in American courts as "additional persuasive evidence"
- It places us and our clients in solidarity with people with disability, their advocates and supporters around the world

And Always

- Include people with intellectual and developmental disabilities in every phase of the project; the CRPD makes clear how fundamental this is, and real inclusion of their voices (“nothing about us without us”) is critical to the integrity and ultimate success of the work