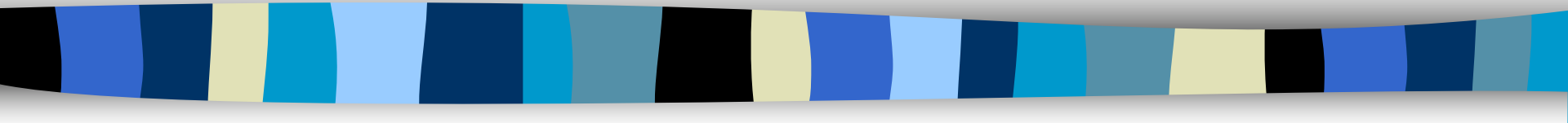


# Protecting Vulnerable Adults: A Human Rights Perspective

Adult Abuse Training Institute, October 30, 2019



Kristin Booth Glen

University Professor and Dean Emerita

CUNY School of Law

SDMNY Project Director



# A List of Non-Harmonious Words

- Abuse: sad, painful, unacceptable, de-humanizing; dangerous
- Protection: Keeping safe from harm, most often by some form of “removal”
- Restorative: Giving back, making whole
- Justice: A claim based on rights; doing what is legally, morally, even spiritually “right”
- Adult : Self-actualizing human being; a “rights-bearer”



# Adult Abuse Protection: From What?

- Financial abuse
- Physical abuse
- Psychological abuse
- Sexual abuse
- Neglect and self-neglect



# Protecting by Removing

- Removing the abuser
- Removing the abused person
- Removing the abused person's control over her finances
- Removing the abused person's right to make decisions because they may be "bad" decisions



# The Endless Dilemma: A Conversation We Need to Have

- Protection vs. autonomy
- How do we balance preventing abuse with maintaining and honoring people's rights?
- This is a world-wide conversation
- People in this room need to be paying attention and joining the conversation from their unique position and standpoint in the work they have chosen
- No answers, but a new framework for asking the questions and finding solutions and a lodestar against which to measure them



# Protection vs. Restoration

- You can't just prosecute your way out of abuse, or take someone from their "dangerous" home into a more restricted setting, or impose substitute decision-making (guardianship) to prevent "bad" or harmful choices
- All of these "protective devices" also bring their own "harms"—isolation, loss of dignity; agency and personhood
- How can we restore what has been taken away or, better yet, retain it even as we "protect"?
- How does our current understanding of "rights" limit the "justice" that should be achieved?



# Why this is so important to figure out now

- Aging population growing, as are the “old old” with the frailties and decline that accompany old age
- Rise (perceived or otherwise) in violence with focus (and blame) on the mentally ill
- Epidemics of addiction, especially opiod related



# Human Rights: A New Framework

- More expansive than U.S. civil rights, which are mostly negative rights
- Relatively unknown in the U.S.
- Good people around the world are trying to make them work, or to fully “realize” them for vulnerable people



# To Begin

- Where do they come from?
- What are they?
- How, in particular, is the realization of these rights by people with disabilities (PWDs) relevant to reconciling the conflicting concepts that this conference surfaces?



# 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
- Inter-connected
- Premised in Equality, Non-Discrimination and Dignity
- Positive (economic, social & cultural rights) as well as Negative (civil rights)
- Owed and promised by the governments of the nations of the world to the people of the world (UDHR)



# 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*...



# Many adults who are abused have disabilities

- Intellectual and developmental disabilities (Down syndrome, Cerebral palsy, Autism spectrum disorders)
- Psychosocial disorders ( schizophrenia, bi-polar disease, depression, etc.)
- Progressive cognitive decline
- Dementia, Alzheimers, etc.
- Traumatic brain injuries (TBIs)
- Mobility impairment; frailness
- Sensory impairments ( Visual, hearing, smell)



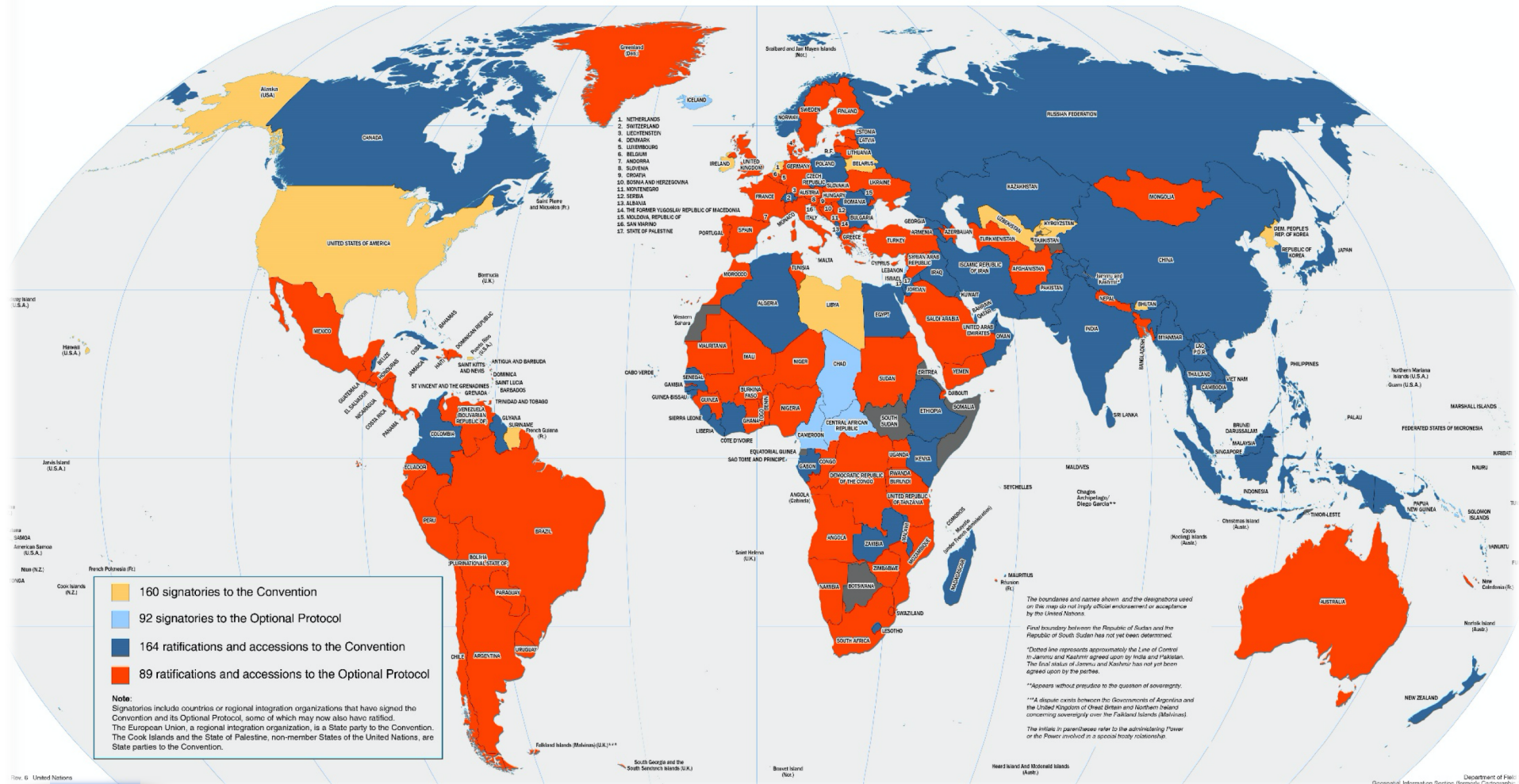
# Purpose of the CRPD

- 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

# CRPD and Optional Protocol Signatures and Ratifications

■ Not Signed   ■ Signed Convention   ■ Signed Convention & Protocol   ■ Ratified Convention   ■ Ratified Convention & Protocol

As of 11 May 2016





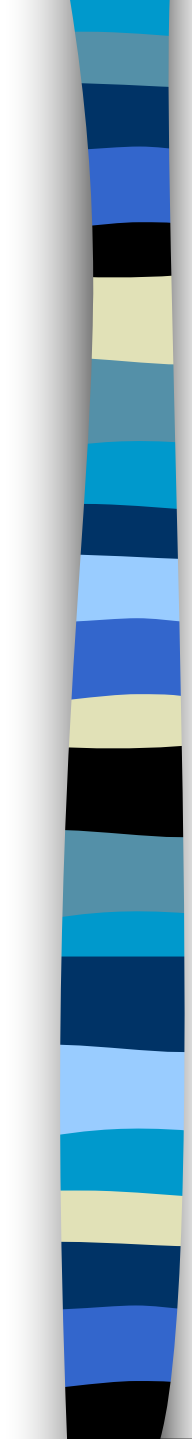
# CRPD Article 16: Freedom from exploitation, violence and abuse

- 1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse...
- 2. States Parties shall provide...for persons with disabilities, and their families and caregivers..information and education on how to avoid, recognize and report instances of exploitation, violence and abuse...



## CRPD Article 16, cont'd

- 4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims...including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the ***health, welfare, self-respect, dignity and autonomy of the person...***



# CRPD Article 19: Living Independently and being included in the community

- a. Persons with disabilities [shall] have the opportunity to choose their place of residence and where and with whom they live...and are not obliged to live in a particular living arrangement
- b. Persons with disabilities [shall] have access to a range of in-home, residential and other community services, including personal assistance necessary to support living in the community, and to prevent isolation or segregation from the community.



# Importance of Article 19.

- “the home...is an extension and mirror of the living body in its everyday activity and is thus a *materialization* of identity..”
- Our homes manifest who we are at the same time as they provide the physical scaffolding that *supports* who we are” Hilde Lindeman, “Holding One Another” in Kittay & Carlson, (Eds), Cognitive Disability and the Challenge to Moral Philosophy, 163-164



## 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... [It] 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: Articles 15, 25, 26
- Financial/Property Decisions: Articles 12(5); 28
- Personal Life Decisions (where to live, relationships, participation, access, employment, mobility and supports) Articles 13, 14, 15, 18, 19, 20, 21, 25, 26, 27, 28, 29, 30



# How Human Rights Can Reconcile Protection and Autonomy: The Example of Article 12

Guardianship is often used as a tool to “protect” vulnerable adults, but by taking away a person’s right and ability to make her own decisions; it violates her autonomy and the right of legal capacity in Art. 12

Recognizing that PWDs may need support to exercise their legal capacity, Art. 12 requires provision of necessary supports to enable them to do so; this is the basis of supported decision-making



# Guardianship

- The legal process by which the right and power to make decisions and enter into legal relationships is taken away from one person because of his/her alleged incapacity, and given instead to another, the Guardian



# What Is Supported Decision-making?

- Supported decision-making (SDM) is “a series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”
  - Robert Dinerstein



# 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



# Kinds of Support

- Gathering necessary information
- Educating the person with I/DD, the Decision Maker (DM) about that information
- Identifying possibilities and alternatives
- Aiding the DM in weighing choices and understanding consequences
- Communicating the DM's decision to others
- Helping to implement the DM's decision



# Supported Decision-Making can take many forms

- Completely informal (so often invisible)
- Circles of support
- Formalized through a facilitated process that may involve a written agreement/contract (SDMNY model)
- Legalized by statute



# Who We Are

- SDMNY is a collaboration among Hunter/CUNY, the New York Alliance for Innovation and Inclusion, the Arc of Westchester, and Disability Rights NY
- SDMNY is the recipient of a 5 year grant from the NYS Developmental Disability Planning Council (DDPC) to create an educational campaign about Supported decision-Making (SDM) and to develop pilot projects to demonstrate SDM as an alternative to guardianship



# The SDMNY Diversion and Restoration Pilots

- Facilitating persons with I/DD (who we call “the Decision Maker”) to choose a person or persons with whom they have trusting relationships to support them in making decisions in specified domains (i.e. health, finances, education, residence, etc.) and to enter into a written document, the SDMA, that incorporates the terms of their agreement



# Diversion and Restoration Pilots. Cont'd

- Diversion: Utilizing the facilitation process and SDMA to make guardianship unnecessary
- Restoration: Utilizing the facilitation process and SDMA to persuade a court that guardianship is no longer needed or in the person's "best interest"



# SDMNY Facilitation: What it *Is*

- It *is*: assisting the parties in creating a process for the way in which the DM will *make decisions* (including decisions that are necessary for the DM to reach her/his goals) with the supports s/he chooses, going forward, hopefully for many years, after the facilitation is completed.
- It *is*: describing and formalizing that process in a Supported Decision-Making Agreement (SDMA)



# But What about Protection?

- Guardianship, although it may be a “last resort”, is not a “silver bullet” and may, through the power to isolate, create conditions for abuse or exploitation: there is no meaningful or effective monitoring
- SDM creates a circle of supporters with “many eyes” to protect against abuse, exploitation or undue influence
- SDM fosters self-determination which results in being “more independent, more integrated into [the] community, better problem solvers, better employed, healthier, and better able to identify and resist abuse”

*National Council on Disability, Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination (2018)*



Add First part of NCD quote



# The National Council on Disability Report continues

- “People with intellectual and developmental disabilities learn through the process of making decisions...It’s not about protecting someone. It’s about teaching them how to best protect themselves”



# Limitations on What We've Done and Learned So Far

- SDM may not work for people with the most severe impairments
- The facilitation model that works for people with I/DD is not directly transferable to other groups
- Pilot projects around the world have mainly focused on PWIDDs, with much less attention to people with psychosocial disabilities and virtually none on older persons with cognitive decline, dementia, etc.



# But Human Rights Can Help Us Meet the Challenges

- Art. 12 (4) deals with the situation where no amount of support can enable a person to express her own decisions, and provides specific protections
- Art. 12 (3) points us to the rights-affirming question to ask as to other vulnerable groups: What supports do they need to exercise legal capacity?
- For people with psychosocial disabilities, who often lack or are alienated from family support, peer support seems promising (Kenya pilot)
- For older persons without natural supports, connecting to community resources; circles of support/relational autonomy; early and universal planning for decisions when capacity is compromised (advance directives, etc.)



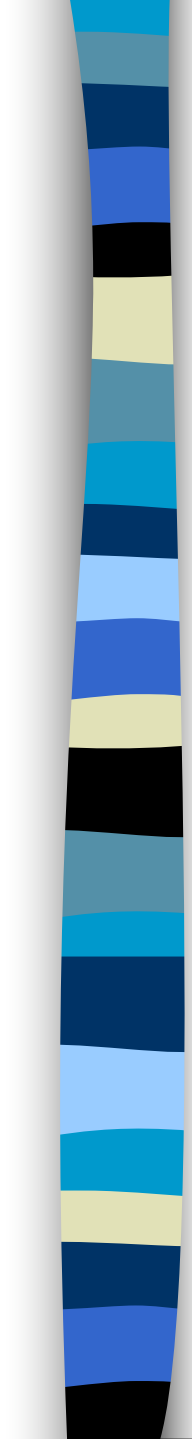
# CRPD Art. 12(4)

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. (emphasis added)



# Importance for Older Persons with Cognitive Decline and/or Dementia

- However worthwhile and valuable what comes in the future may be...it will not include greater freedom or autonomy. When freedom is curtailed in early dementia, it is final chances that are being foregone, not first chances with plenty of second chances to come. These are the last times something will be attempted or done,

- 
- and perhaps it is a recognition of this, however dimmed by disease, that makes the desire to do something so curiously linger, even intensify, after the physical or mental capacity to do it safely has begun to slip away.
  - Bruce Jennings, *Freedom Fading: On Dementia, Best Interests and Public Safety*, 35 Ga. L. Rev. 593, 609 (2001)



# Universal Declaration of Rights: Preamble

- Whereas recognition of the inherent dignity and of the equal and inalienable rights of *all the members of the human family* is the foundation of freedom, justice and peace in the world...



# Some On-Line Resources: SDM Generally

- [www.sdmny.org](http://www.sdmny.org): New York SDM pilot projects and resource library( cases, articles, statutes, etc.)
- [www.supporteddecisions.org](http://www.supporteddecisions.org): CPR pilot project, evaluations and resource library
- [www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org): National Resource Center on Supported Decision-Making; state by state information and resource library



# On Line Resource: SDM and Dementia

- <https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/>. A fulsome website based on research and practice at the Cognitive Decline Partnership Centre of the University of Sydney with numerous resources including policy guidelines, videos, staff training packages, etc.