

# HEALTH MANAGEMENT ASSOCIATES

**#FreeBrittany, #FreeGrandma, #FreeUsAll**

## **Are We Overdue in Our Reform of Guardianship Law and Practice?**

---

### **HCBS Conference 2021**

Sharon Lewis, Heath Management Associates

David Hutt, National Disability Rights Network

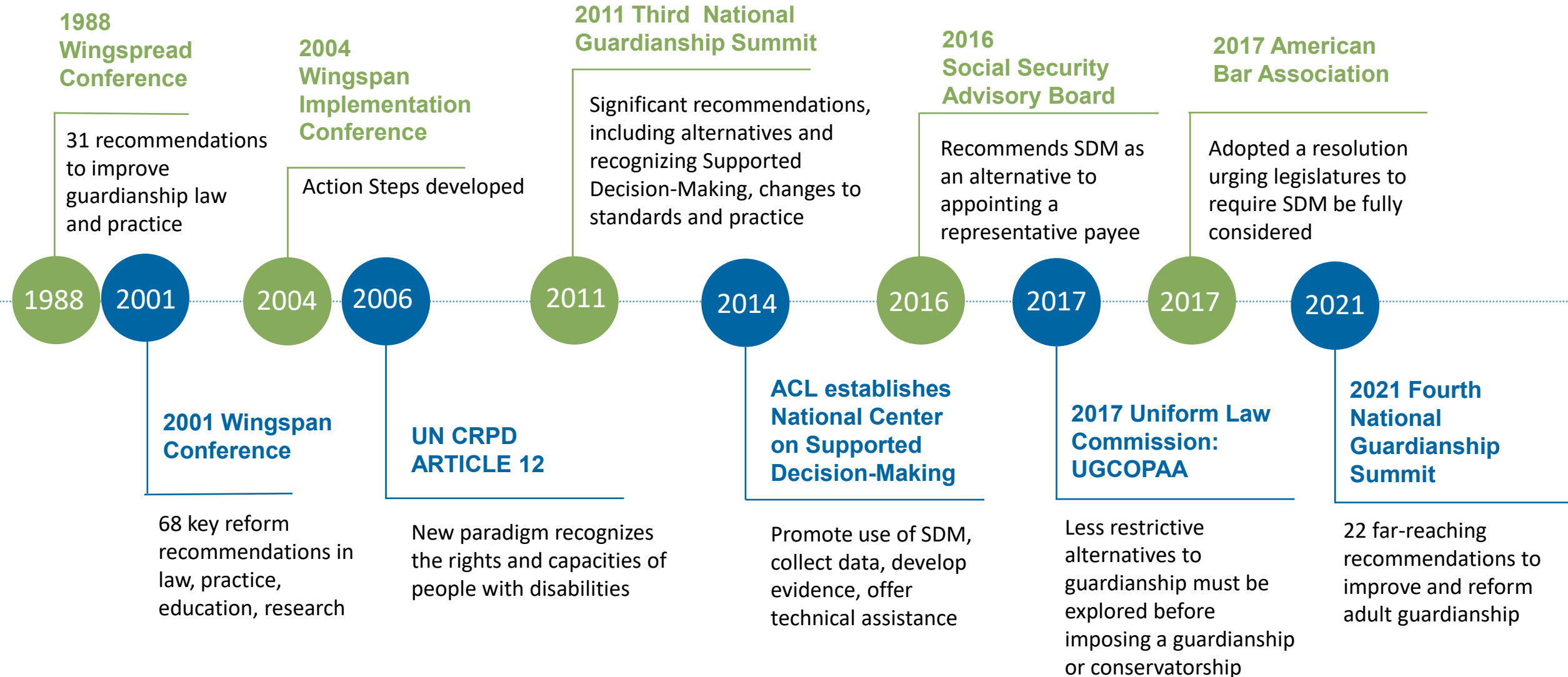
Dari Pogach, DC Department of Aging and Community Living

Roger Bearden, NYS Office for People with Developmental Disabilities

## ■ REFORMING GUARDIANSHIP, CONSERVATORSHIP AND OTHER PROTECTIVE ARRANGEMENTS

- + **FreeBrittany movement** and other celebrity cases – bringing the issue into the mainstream conversation
  
- + **History:** Reform movement accelerated by UN Convention on the Rights of persons with Disabilities (CRPD); Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA); American Bar Association; National Guardianship Network; and individual state actions
  
- + **In 2021:**
  - + Research findings on supported decision-making pilots, Virginia, Massachusetts, New York
  - + National Guardianship Summit, May 2021
  - + Senate legislation : Guardianship Accountability Act (S. 2881; Senator Susan Collins and Senator Bob Casey)
  - + Senate Committee on the Judiciary, Subcommittee on The Constitution hearing, “Toxic Conservatorships: The Need for Reform” September 28, 2021 <https://www.judiciary.senate.gov/meetings/toxic-conservatorships-the-need-for-reform>
  
- + **Importance within context of HCBS:** Balancing rights, freedoms and health and safety

# KEY MOMENTS IN GUARDIANSHIP REFORM: A LONG TIME COMING



## ■ UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

- **Sets out that people with disabilities:**

  - “have the right to recognition everywhere as persons before the law.”

  - “enjoy legal capacity on an equal basis with others in all aspects of life.”

- **Rejects the traditional legal structure of “best interest” or “substituted judgement” and honors the human rights of ALL people**

- **Proposes that states/countries shall:**

  - “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

  - “ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards that prevent abuse in accordance with international human rights law.”

## ■ ALTERNATIVES TO GUARDIANSHIP: HCBS CONTEXT

### + Implications for Medicaid HCBS

- + Person-centered thinking and planning
- + Facilitating and supporting informed choice
- + Understanding individual situations and limited rights restrictions
- + Developing self-efficacy and decision-making skills to support dignity, autonomy, rights and freedoms
- + Engaging circles of support and addressing conflict of interest
- + Need for outreach, learning, education and research
- + Guardianship preference/convenience do not eliminate provider HCBS settings requirements

### + **NCI data brief:** Compared to people without guardians, people with IDD with guardians are less likely to make important life decisions including:

- + where to live (46.0% vs. 68.5%)
- + who to live with (33.8% vs. 55.5%)
- + their daily schedule (80.1% vs. 89.8%)
- + what to buy with their spending money (86.7% vs. 94.1%)

[https://www.nationalcoreindicators.org/upload/core-indicators/NCI\\_Data\\_Highlight\\_Guardianship\\_2021\\_Final.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/NCI_Data_Highlight_Guardianship_2021_Final.pdf)

# **THE FOURTH NATIONAL GUARDIANSHIP SUMMIT**

## **RECOMMENDATIONS TO PROMOTE REFORM**

**David Hutt, National Disability Rights Network**

# Highlights of National Guardianship Summit

- Held virtually over four half-day sessions starting on May 10, 2021 around the theme of **Maximizing Autonomy and Ensuring Accountability**.
- First national summit held to develop recommendations in ten years.
- The National Guardianship Network, a collaboration of fourteen organizations interested in guardianship issues organized the summit.
- Syracuse University College of Law hosted the event.



# Highlights of National Guardianship Summit

- **125 summit participants**, including attorneys, advocates, family guardians, judges, law professors and scholars, and observers from the federal government and other countries.
- National Guardianship Network organizations and other sponsors sent voting delegates.
- Participants were divided into **six working groups**.
- On the final day of the summit, participants discussed, debated, and amended draft recommendations, which were voted on by the delegates as adopted by the summit.





# Highlights of National Guardianship Summit

- Summit papers and the recommendations will be published in a symposium edition of the *Syracuse Law Review* (likely this fall).
- Current drafts and issues briefs are currently available on the Summit website at: <http://law.syr.edu//academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability>.
- Recommendations are included in conference materials and available on the Summit website.



# Highlight of Summit Recommendations

## Twenty-two Recommendations for Improvement and Reform

- Rights-Based Guardianships - Enhancing Rights of Persons Subject to Guardianship: 3 Recommendations
- Supporting Decision-Making: 4 Recommendations
- Limited Guardianship, Protective Arrangement & Diverting Pipelines: 4 Recommendations
- Rethinking Guardianship Monitoring & Addressing Abuse: 4 Recommendations
- Addressing Fiduciary Responsibilities & Tensions: 4 Recommendations
- Guardianship Court Improvement Programs: 3 Recommendations



## **Contact information:**

David T. Hutt, Ph.D.

Deputy Executive Director for Legal Services and General Counsel

National Disability Rights Network

[david.hutt@ndrn.org](mailto:david.hutt@ndrn.org)



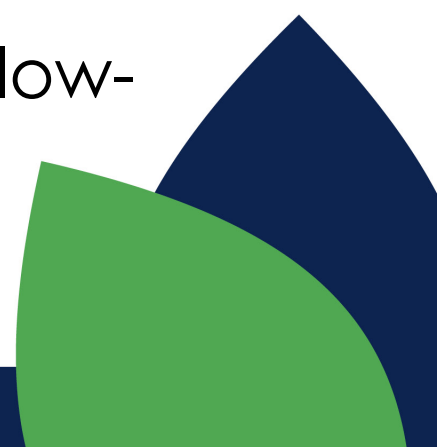
# DEPARTMENT OF AGING AND COMMUNITY LIVING

Dari Pogach, Interim Community Services Administrator

[dari.pogach@dc.gov](mailto:dari.pogach@dc.gov)



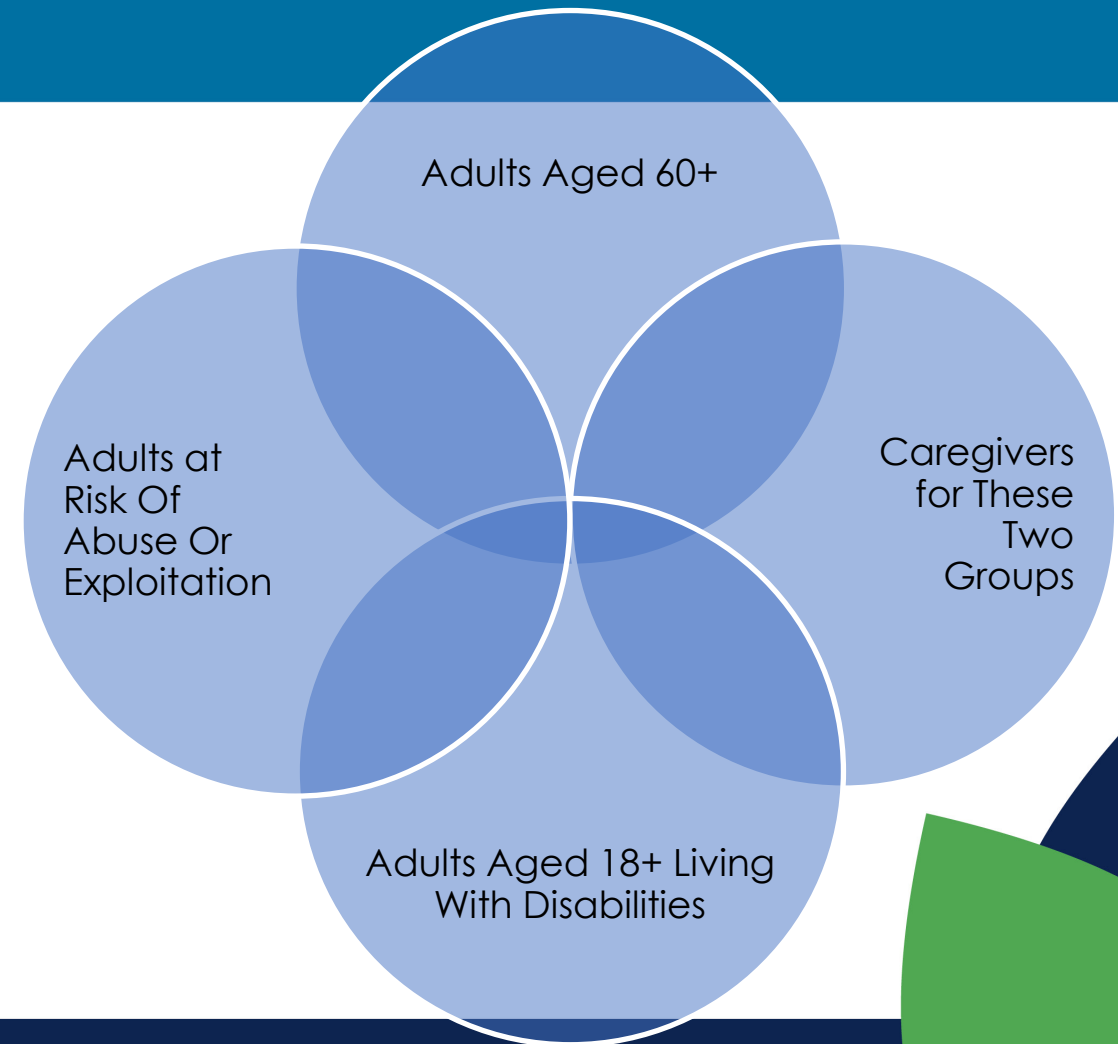
# ABOUT US

- The Department of Aging and Community Living serves as the District's State Unit on Aging and an Area Agency on Aging.
  - We advocate, plan, implement, and monitor programs in health, education, and social services for seniors, adults with disabilities and caregivers.
  - In partnership with more than 20 community-based organizations across the city, we offer more than 40 free or low-cost programs to help all District residents live boldly at any age, stage, or ability.
- 

# POPULATIONS SERVED

## **DACL's core populations are:**

1. DC Residents, age 60 and older
2. DC Residents, age 18 and older living with disabilities
3. Caregivers for these two groups
4. Adults at risk of abuse or exploitation



# SERVICES INCLUDE

- Adult Protective Services
- Case Management
- Nursing Home Transition
- Caregiver support
- In home supports
- Adult day health programs
- Nutrition/home delivered meals

# MULTIDISCIPLINARY GUARDIANSHIP DIVERSION PROGRAM (3.3)

- Every state should have a guardianship diversion program tasked with facilitating alternatives to guardianship, reducing the likelihood that guardianships will be granted where not necessary, and monitoring for the continued need for the guardianship.
- Such programs could be operated as a multi-disciplinary approach in collaboration with schools, adult protective services, healthcare, aging and disability service providers, the legal community, and other entities...



# TRAINING (3.4)

- *States* should provide accessible, practical and tailored training to individuals and entities known to be pipelines to plenary guardianship (e.g., lawyers, judges, schools, nursing homes, health care providers, evaluators, investigators, adult protective services) on (1) the impact of guardianship; (2) legal and ethical obligations to exhaust alternatives to guardianship before pursuing it; (3) alternatives to guardianship including supported decision-making, formal and informal services and supports, advance directives, voluntary fiduciaries, other legal and non-legal interventions; and (4) orders that are limited in scope and limited in time.



**Office for People With  
Developmental Disabilities**

# **Alternatives to Guardianship in NYS**

# NY Guardianship Framework

- Two separate guardianship statutes in New York State
- Application depends on diagnosis
  - SPCA Art. 17a – applicable to people with intellectual or developmental disabilities
  - MHL Art. 81 – applicable to any person who may have diminished capacity
- Efforts at legislative reform unsuccessful

# Developing Alternatives

- Stakeholders identify supported decision-making as less restrictive alternative to guardianship in 2012
- Robust stakeholder dialogue between 2012 and 2015 to build consensus around a model
- NYS Developmental Disabilities Council issued RFP in 2016 to fund supported decision-making pilot program



# Pilot Development

- Supported Decision-Making New York (SDMNY) created in 2016 in response to DDPC RFP
- Goal was to educate stakeholders and the public about supported decision-making and to pilot its use for people with I/DD

# SDM Pilot

- 5 locations: NYC, Long Island, Westchester, Capital Region, Rochester
- Trained 3rd party facilitators to support decisionmaker and their supporters, as chosen by the decisionmaker
- People with I/DD create supported decision-making agreements (SDMAs) about the areas in their lives for which they'd like support making decisions.
- Informational campaign for school-aged youth and parents, to inform them about alternatives to guardianship.

# Results

- 200 facilitators trained to help Decision-Makers and supporters create SDMAs across the state.
- 200+ Decision-Makers working with facilitators to create SDMAs, with 77 fully signed SDMAs.
- Over 5000 stakeholders educated through the campaign efforts

# SDMNY Evaluation

- Increased confidence and self-advocacy for decisionmakers
- Reduced concerns of parents/potential future guardians about long term viability of guardianship



# Next Steps

- Seek legislative recognition of supported decision-making agreements
- Continue pilot program with ARPA funds
- Promote facilitation as fundable activity for people with self-directed budgets and explore future funding opportunities



## ■ GUARDIANSHIP REFORM AND ALTERNATIVES – NATIONAL RESOURCES



- + The Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability: <http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability>
- + Uniform Law Commission Guardianship, Conservatorship, and Other Protective Arrangements Act: <https://my.uniformlaws.org/committees/community-home?CommunityKey=2eba8654-8871-4905-ad38-aabbd573911c>
- + Department of Justice information: <https://www.justice.gov/elderjustice/guardianship>
- + National Center for State Courts, Finding the Right Fit: Decision-Making Supports and Guardianship, <https://eji.courtims.org/index>
- + American Bar Association:  
[https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/)
  - + ABA Toolkit: [https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/practical\\_tool/](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/)
- + National Guardianship Association Position Statements: <https://www.guardianship.org/advocacy/position-statements/>
- + National Center for Supported Decision Making: [www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)
- + Center for Public Representation Supported Decision-Making: <https://supporteddecisions.org/>
- + National Council on Disability, Beyond Guardianship: [https://ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf)
- + ACLU Supported Decision-Making Resource Library: <https://www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library>