

SDMNY ENTERS THE NATIONAL CONVERSATION ON NEW AAIDD GOALS FOR NATIONAL HEALTH EQUITY

Louisville may be best known as the home of the Kentucky Derby, but last week it hosted an event of greater significance for our community, the annual meeting of the oldest and largest interdisciplinary membership organization of professionals and others concerned with intellectual and developmental disabilities, the American Association for Intellectual and Developmental Disability (AAIDD). We were delighted that SDMNY Director Naomi Brickel was able to attend, and especially proud that she was invited to participate in the first planning meeting for AAIDD's decadal project, its influential 2024 National Goals for Health Equity.



Louisville, Kentucky

Every 10 years working groups of experts convened by AAIDD review the literature, policy and best practices in the field in selected "strands" (this year's were Social Determinants of Health; Disability Competent Health Care; Financing/Delivery Systems; Health Promotion; Consent/Decision Making; Public Policy/Systems Design; Issues of Adulthood [life transitions, reproductive health, aging]; Mental and Behavioral Health; and Ethical Issues.)



AAIDD headquarter in Maryland

Each working group is charged with developing a short list of national research, practice, and policy recommendations to enhance the quality of life for people with IDD. Naomi was a chosen expert in the Consent/Decision Making Strand which included 10 people of diverse perspectives, including researchers, clinicians, practitioners, policy makers, and people with lived experience of disabilities. Together they engaged in high-level discussions, suggesting national goals that could be achieved in 10 years, and developing a set of recommendations for achieving those goals. The work will continue, with follow-up development of a book chapter, policy brief, and journal article to inform stakeholders and promote the recommendations, including, thanks largely to Naomi's participation, SDM and the model we have created at SDMNY. Among the preliminary recommendations are:

- universal policies for supported decision-making; building and supporting state SDM and SDMA laws; clarifying a definition of SDM and informal and formal supports and systems; developing, building, and testing how to inclusively share information and build expectations for human and civil rights – educating families, people with disabilities, and other professionals.

While many states have SDMA statues, none, except ours, requires a rigorous facilitation process (or, indeed, any education at all) for Decision-Makers and their supporters as a condition of extending legislative recognition. Advocacy groups in other states may offer information and limited assistance in creating SDMAs, but lack statutes that would prevent discrimination against Decision-Makers who have created them. Our experience, based in the human right of legal capacity, encompasses both the right to make one's own decisions, which includes utilizing SDM as a less restrictive alternative to guardianship, and the right to have those decisions accepted by third parties without discrimination, which is accomplished by our groundbreaking SDMA law. Our experience is, by now, extensive, robust and unique, creating a viable and proven principled practice and policy model for other jurisdictions.

Reflecting on her experience last week, and looking forward to her continued work on the project, Naomi says: "Underlying all of our overall group recommendations is a challenge to society and systems to shift the accountability from the person with IDD to prove their 'capacity' back on to the systems and society to become more effective in communicating and accommodating all."

BRAVA NAOMI, AND THANKS TO AAIDD!