NEW UN REPORT GIVES A SHOUT OUT TO SDM

Within the United Nations, the position of “Special Rapporteur” (Independent Expert) is appointed by the UN Commission on Human Rights to report and advise on subject matter or country specific subjects. Since 2014 there has been a Special Rapporteur on the rights of persons with disabilities; recently that position has been filled by our friend Gerard Quinn of Ireland, who is perhaps the world’s leading expert on the human right of legal capacity and SDM.

The UN has just released a groundbreaking report written by Gerard, Transformation of Services for Persons with Disabilities (click below to read the full Report and/or an Easy Read version) that is premised in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), the right to live in the community. As we have said many times, the CRPD, and especially Article 12, the right to legal capacity, is at the heart of SDMNY’s work, and the Report makes the strong and necessary connection between the right and ability to make one’s own decisions, and the right and ability to live an inclusive life.

In re-imagining services in the 21st century that could actually foster these rights, the Report argues that traditional service and support models often perpetuate dependency and lack of agency that focus on impairments, considering people with disabilities as passive recipients of care, rather than being grounded in personhood, autonomy and community inclusion, as the CRPD requires. For this reason, the Report calls for “a wholly new philosophy of service and support”. To that end, it continues:

“It is hard to talk about the formal right to live independently and be connected to the community without talking about the kind of services needed to make it a reality…Our inherited disability services system owes much to the medical model of disability…[where]the focus was on the impairment, not the person. Moral agency and legal capacity—the control of persons over their own lives—was not the goal…In this sphere, as in many others, the [CRPD] is a game-changer…the starting point is the humanity and the just claims of persons with disabilities as human beings with equal rights, hopes and dreams…Services of the future should primarily be about enabling one to self-actualize in the world…point[ing] strongly toward the personalization of services…especially in support models for decision-making.” (emphasis added)

Making the world better for people with I/DD isn’t easy, but human rights gives us a powerful framework. One of the Report’s final recommendations, calling for “developing protocols on supported decision-making in the specific context of services” resonates clearly with our current OPWDD grant focus on including SDM within Self-Direction, and reaffirms how deeply our work is committed to advancing the human right of everyone to make their own decisions regardless of disability.