AN SDMA SIGNING WITH A "CHOSEN FAMILY" OF SUPPORTERS

Many of our Decision-Makers are transition age or in their early 20's, still have close family, choose parents as supporters, and often still live at or near their family home. Older Decision-Makers, however, may no longer have biological family members active in their lives, and many live in residential communities or other forms of supported housing. Since SDM is about making one's own decisions with the support of "trusted persons in their lives" their choice of supporters may look quite different, though it is equally important. Just as neurotypical people have non-biological "chosen families", so also do people with I/DD, and it is important that they can choose supporters from those families.

Indiria, who celebrated the signing of her SDMA last week, is a perfect example. She lives in a residential community in Amsterdam, NY (in the Mohawk Valley) run by Liberty ARC where she is an active and engaged member, serving on the Family Support Service Board Committee and volunteering in a food pantry. She is 52 and has lived at Liberty for almost 40 years, developing deep relationships with support workers, including, especially, Supporter Roxanne, and her fellow residents, including her best friend Marisol. Roxanne has been working with Indiria for over 20 years, and Marisol and Indiria (who says she is "like a sister") have known each other since they were 13. They, and other workers and friends have truly become Indiria's family.

Judging from the signing celebration, it seems like just about everyone in the community was involved and excited, both for Indiria and about SDM. Indiria has been educating others about her SDM journey through her membership on the Self Advocacy Committee, and although this is Liberty's first SDMNY facilitation and signing, Liberty ARC CEO Jennifer Saunders says "It was a wonderful ceremony and a time for celebration of this major milestone for Indiria. We are excited to be able to support her, and hopefully others, as they pursue supported decision-making."

Liberty ARC COO Candy, Supporter Brenda, Supporter Roxanne, DM Indiria, Supporter Debby

The ability to choose trusted support staff as supporters is, we believe, critical, especially for older adults in residential settings. It is also something we fought successfully to include in New York's SDMA legislation –and the value of which we had demonstrated over the 5 years of our DDPC-funded pilot project. Many of the other states that have SDMA statutes explicitly prohibit employees of agencies that provide services to a person from serving as supporters (though exceptions are made in some statutes for relatives.) We believe that the ability to make one's own decisions is a human right, and that it must include the decision as to who a person wants to support them. Both our statute and the recently posted implementing regulations (Good News 8/9/2024) make this clear.

At her ceremony Indiria said "I'm independent" and "I'm so excited and proud." "I'm the type of woman who makes my own decisions. It's kind of difficult to have somebody else make my decisions when I can do it. [Having] a Supporter is one thing, but the decision must be mine. I can't rely on someone to do it for me, I have to be the person." Her friends and supporters echoed her sentiments. Roxanne affirmed the importance of SDM which, she said, allows "[y]ou [to] live your best life!" Candy, the Chief Operating Officer of Liberty ARC said "I have known Indiria for so many years – we have been friends for such a long time and I'm just so excited about this process because it's the law now and it gives her the ability to make those decisions in her life, teaches her to make decisions and to feel good about her decisions. So I'm so excited that she now has the right to do that."Marisol summed up everyone's feeling when she said:

"Way to go, Indiria, I'm proud of you!"

We are proud too, both of Indiria and how her story affirms not only her *right* to choose her supporters, but the *value* of doing so from her "chosen family."

CONGRATULATIONS INDIRIA, HER SUPPORTERS AND FAMILY AT LIBERTY ARC, AND FACILITATOR RACHEL!