Looking Back, Looking Forward

An Evaluation of the Supported Decision-Making New York Project (SDMNY), with Recommendations to Increase Knowledge, Use, and Acceptance of Supported Decision-Making in New York State

Supported Decision-Making New York (SDMNY) is a partnership including Hunter College/City University of New York and the New York Alliance for Inclusion and Innovation. SDMNY received a 5-year grant from the Council on Developmental Disabilities (formerly known as the Developmental Disabilities Planning Council) to educate and empower New Yorkers with developmental disabilities to use Supported Decision-Making. The Burton Blatt Institute (BBI) at Syracuse University was selected to independently evaluate SDMNY. The following is a summary of their findings.

If you want more information on the full report, you can reach out to information@cdd.ny.gov

Project Impacts

Participant Results

Over the grant's 5 years, SDMNY served 125 people with developmental disabilities. SDMNY calls these participants "decision-makers". BBI extensively interviewed 23 decision-makers who completed the SDMNY process. The interviewed decision-makers overwhelmingly enjoyed the SDMNY program. Most decision-makers stated that working with SDMNY helped them:

- be more in control of their decisions,
- better advocate for themselves,
- better say what they want and need, and
- improve their quality of life

Supporters of these decision-makers agreed that SDMNY had improved life for the decision-makers.

Outreach and Education

SDMNY did more than the hands-on work with decision-makers and their supporters. The project also engaged in a lot of education and outreach. They created an impressive set of educational materials and presentations on supported decision-making. SDMNY held hundreds of outreach and education sessions with several stakeholders.

These Included:
- people with developmental disabilities
- family members
- educators
- legal staff
- judges

Additionally, they created educational videos and written materials. Some materials showed the importance of choice. Others showed the ways that supported decision-making can help people with disabilities understand and make decisions. These and many other materials are now hosted on their website: SDMNY.org

Systems Change

SDMNY resulted in real systematic change. They had a major impact on legislation with their series of recommendations for Supported Decision-Making Legislation. In 2022, New York passed legislation that recognizes people with developmental disabilities right to use supported decision-making agreements as an alternative to guardianship and provides legal recognition for Supported Decision-Making Agreements. The law essentially adopts the principles and recommendations set out by SDMNY in their publication. This legislation clearly states that there are ways "formal and informal" for people to use supported Decision Making. Also "the availability of supported decision-making agreements is not intended to limit the informal use of supported decision-making." Despite some issues with the legislation evaluators felt that this law is one of the most effective in the country at promoting self-determination.

Limitations and Lessons Learned

BBI faced some barriers in their evaluation. Primarily, they were unable to get interview data from those who didn't complete program. About half of decision-makers dropped out before fully completing SDMNY's program. Because they could not be reached for interview, we can't know with certainty why these decision-makers chose not to complete the program. But evaluators did have strong theories.

Process Length

The model takes a long time to complete. Additionally, for some, there were significant delays at the beginning of the process. On average it takes 18 months for a decision-maker to complete the required 3 phases of SDMNY's model. Sometimes a decision-maker did not work well with their first facilitator. Requesting and getting another facilitator might take 3-6 months.

These long delays were due in part to the nature of the model. Decision-makers could not take part in the program unless they have a facilitator. Facilitators could only work with decision-makers once they had a mentor. A person could only become a mentor after facilitating a certain number of decision-makers. And SDMNY leadership had to review all supported decision-making agreements before participants could sign. The goal was to prevent supporters having undue influence over decision-makers. However, if there were not enough functioning facilitators, mentors, and reviewers the whole process stalled.

Model Flexibility

The model piloted by SDMNY has three distinct phases. In phase one decision-makers identify:

- what areas they want support in
- who they want support from
- what type of support they want
- how they want to be supported.
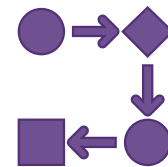
They fill out these answers in a "Big Four Chart". Then they use this chart to draft an agreement.

In phase two decision-makers invite the people they identified as supports to get involved. They will work with decision-makers and a facilitator to identify how supporters can and will help the decision-maker.

In phase three they all work to create a finalized Supported Decision-Making agreement. The agreement is reviewed by a mentor and then SDMNY leadership. Once everything is approved, they have a "signing ceremony".

This length and rigidity were a barrier to many. Sometimes decision-makers didn't feel they needed to do every phase before creating an agreement. Or they wanted to go through the phases more quickly. However, this model was inflexible and the system around it didn't allow for an abbreviated version. Some felt this made the program very "all or nothing".

Additionally, SDMNY only piloted one model for supported decision-making. For those that completed the program it was very successful. But the large dropout rate suggests that there is room for other models in the field as well. There is no "one-size-fits-all" solution to supported decision-making. It is about self-determination. Decision-makers have the final word on what is best for them. Best practices suggest Decision-Makers should not be required to use a particular methodology or form. Instead, participants should create the plan that works best for them.

Outreach Gaps

Evaluators were impressed with the depth and variety of resources created by SDMNY in their education and outreach. But they did identify some areas where outreach could improve. Health care providers were one such area. It is often healthcare providers who recommend guardianship for people with developmental disabilities. Additionally, evaluators felt SDMNY could do a better job reaching out to support agencies and families. These are some of the people who most often see people with disabilities making decisions, receiving support and using the principles of Supported Decision-Making. Reaching these stakeholders could have a huge impact on long term outcomes.

Recommendations

Increase Outreach and Education

Education should be increased in two main areas. People with Developmental Disabilities, family members and professionals should know of Supported Decision-Making as an alternative to guardianship. Outreach should build constructive relationships and meet people where they are at. There will always be those who have a good-faith belief that guardianship is beneficial. But non-judgmentally teaching the benefits of self-determination and the effectiveness of Supported Decision-Making is a more effective way to increase understanding than an "all-or-nothing" approach. Telling someone, for example, that guardianship should not even exist, alienates potential partners and participants and can turn them away from supported decision-making options. We all want the person with the disability to be safe and succeed in their goals. This is a good starting point for discussion. Supported Decision-Making can be introduced as a "first step" towards independence.

Education and outreach should also be used to encourage people to incorporate supported decision-making into existing supports and services. Supported decision-making is more than just an alternative to guardianship. It is a value set. Using the values of supported decision-making in existing programs can improve services. It will empower people with disabilities to develop and practice their decision-making skills. Then they can use these skills to reach their goals and dreams.

Collaborate with State Agencies

Outreach to incorporate supported decision-making into state-operated supports and services could have a huge impact. Particularly in services people with disabilities are likely to access. For example, special education, vocational rehabilitation, and Medicaid.

Research shows that special education designed to increase self-determination helps students:

- grow to be more employed
- live independently
- be more active in their communities.

Furthermore, when parents and guardians were asked who first suggested they seek guardianship, the most common answer was "school personnel". Incorporating supported decision-making into special education can improve post-graduate outcomes and reduce guardianship rates.

State vocational rehab programs such as ACCES-VR support people with disabilities to find and succeed in jobs that are a good match for them. By incorporating supported decision-making into this process, people will be empowered to make truly informed choices. They can practice decision making-skills that help in all life areas. People with disabilities will truly shape their own supports and services.

Conduct or Sponsor More Research

More research can help to identify best practices in supported decision-making. The model of SDMNY was shown to be extremely helpful and effective for participants who completed it. But just as many dropped out before completing the process. Supported Decision-making is not a one size fits all process. By exploring and evaluating other methods and models, we can improve outcomes across the state.

Other councils have seen success with broader models. A pilot project from the Virginia council, for example, did not require participants to use a certain method or plan. Instead, participants created the plans that worked best for them resulting in a variety of options. All the participants interviewed following participation reported that because of the project they were better at making decisions, had better relationships with their friends and families and improved their lives.

Self-determination is a basic tenet of Supported Decision-Making. This should be reflected in Supported Decision-Making models and practices. Everyone comes to the process from a different place. Decision-makers will have differing skills, needs, and

desires. Therefore, it is important that people have options. Supported Decision-Making programs should be adaptable. Programs should meet people where they are at and take them to where they want to go.

Educate Legislators and Policymakers

It is our responsibility to educate policymakers so that they can make the most informed choice. SDMNY evaluators liked many aspects of the recent legislation. However, they still had concerns. Particularly they were concerned about section 82.10 (D) which specifies that for Supported Decision-Making agreements to be legally enforceable they must be signed by a facilitator or educator and created in a "recognized facilitation and/or education process". Evaluators fear that this provision could end up limiting the rights of people who have been using a different model of supported decision-making or who can't or don't want to undergo the facilitation and education required.

Further, they expressed concerns that the law may incentivize third parties to disregard decisions made by people with developmental disabilities. For example, by the language of the law, health care providers who honor supported decisions made by people who have undergone the facilitation or education process cannot be sued for doing so. But this doesn't apply to decision made by a person using their own Supported Decision-Making process. So, health care providers may choose not to honor the decisions of these individuals without seeing some proof of a signed supported decision-making agreement.

Evaluators stressed that this section of the law could limit the decision-making rights of people who have developmental disabilities but have not undergone the facilitation process. People without disabilities have the right to make decisions without a facilitation process. Yet people with developmental disabilities may be required to prove their ability to do so through undergoing facilitation and education first.

In addition to informing legislators about the existing legislation, we should partner to build opportunities for public comment on policy going forward. Through this education we can accomplish the true aim of maximizing people with developmental disabilities rights to make decisions and have them honored.

Finally, evaluators recommended that the Council on Developmental Disabilities (CDD) create a series of position papers. These policy papers could be used to educate legislators and policymakers on issues important to people with developmental disabilities. The voice of the council is in a unique position to make change across the state.