The Estimated Economic Impact of Facilitated Supported Decision-Making in New York

Prepared for: Supported Decision-Making New York and The New York Community Trust

October 11, 2022

STOUT

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Section I
Stout Profile and Qualifications

1. Stout Risius Ross, LLC (Stout) is a global investment bank and advisory firm specializing in corporate finance, valuation, financial disputes, and investigations. In addition to these services, Stout's professionals have expertise in strategy consulting involving a variety of socioeconomic issues, including issues of or related to access to justice and the needs of low-income individuals and communities.

2. Under the direction of Neil Steinkamp, who leads Stout's Transformative Change Consulting practice, Stout is a recognized leader in the civil legal aid community and offers the following services:

    - Economic impact assessments and policy research for civil legal aid initiatives;
    - Strategy consulting and action plan development for issues relating to access to justice;
    - Non-profit budget development, review, and recommendations;
    - Cost-benefit and impact analyses for non-profit initiatives and activities;
    - Data-driven program evaluation and implementation; and
    - Dispute consulting and damages analyses for low-income individuals.

3. Neil Steinkamp is a Managing Director at Stout in the firm's New York City office. He has extensive experience providing a broad range of strategic, business, and financial advice to business and community leaders and their advisors.

4. Mr. Steinkamp has nearly 20 years of experience covering many industries and matter types resulting in a comprehensive understanding of the application of strategic assessment, risk analysis, financial consulting, and other complex analyses. His work has involved complex problem solving involving large-scale industry and social issues. In certain matters, he has provided testimony during bench and jury trials, domestic and international arbitration, as well during city council hearings. He has also assisted parties in a variety of complex resolutions involving settlement negotiations, mediation, and facilitation.

Section II
Executive Summary

5. Stout was engaged by Supported Decision-Making New York (SDMNY) to perform an analysis of the estimated potential economic impact of facilitated supported decision making (facilitated SDM) and supported decision-making agreement (SDMA) legislation to New York.

6. **Key Findings.** Stout's research and analyses resulted in three key findings related to facilitated SDM: (1) in any reasonable distribution of scenarios where facilitated SDM is used by people with developmental disabilities (PWDD) as an alternative to the current system, New York will recognize a significant positive economic benefit; (2) New York Surrogate's Court would likely realize significant value through increased efficiency, effectiveness, and better use of court resources related to fewer guardianship filings as a result of facilitated SDM; and (3) with an annual investment of $3.5 million from New York in facilitated SDM that state could recognize annual economic benefits of $9.6 million – that is, for every dollar invested in facilitated SDM, New York could recognize annual cost savings of $2.75, in addition to other benefits, as discussed below.

7. **Facilitated SDM and Legally Recognized SDMAs.** We all engage in supported decision-making (SDM) in that we often seek support from trusted people in our lives when making decisions. Facilitated SDM is a formal process that ensures the efficacy of SDM. Facilitated SDM is a process whereby a PWDD, called "the Decision-Maker," works with a trained facilitator to determine the areas in which they want decision-making support, the kinds of support, and the trusted persons in their life from whom they want that support. This process culminates in a written SDMA negotiated among and signed by the Decision-Maker and their chosen supporters. When decisions made pursuant to SDMAs are legally recognized through SDMA legislation, third parties are required to accept those decisions and precluded from making their own capacity determinations, unless certain exceptions apply.

8. **Facilitated SDM and Guardianship.** A primary reason for recent interest in SDM is its use as a less restrictive alternative to guardianship.[1] Guardianship is the legal process by which a court removes a person's power and ability to make their own decisions and gives that power to another person – the guardian. Guardianships for PWDD can inhibit personal growth, empowerment, self-determination, and community inclusion.[2] Guardianship is

[1] American Bar Association Resolution 113. 2017.
[2] "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities." National Council on Disability. March 22, 2018.

also often presented as "protective" for the PWDD, though advocates and stakeholders argue that it denies PWDD the dignity of risk and autonomy over their lives.[3]

9. **Economic Benefits to New York Related to Facilitated SDM and SDMA Legislation.** Stout quantified the estimated potential economic benefits of facilitated SDM and/or SDMAs to New York using a net present value scenario approach. This approach considered a range of scenarios where costs associated with guardianship, residential habilitation/congregate care, emergency department care, or generalized services may be reduced because of facilitated SDM and SDMAs. Stout used a net present value calculation for the range of scenarios to estimate the economic benefits that New York may realize if facilitated SDM / legally recognized SDMAs were widely available. The four primary scenarios Stout analyzed, and that experts on SDM and guardianship and stakeholders from across New York indicated would be reasonably expected, were:

    - Decreased use of guardianships;
    - Delaying use of residential habilitation services and other forms of congregate care;
    - Enhanced self-determination, and the associated decrease in the use of HCBS Medicaid Waiver and State Plan services; and
    - Decreased use of emergency department care.

10. Stout's analysis showed that in each of these scenarios, there is a positive net present value indicating expected net economic benefit to New York greater than the costs of administration. There may be unique, rare scenarios where a Decision-Maker using facilitated SDM does not achieve outcomes that would result in a positive net present value. However, over any reasonable range of scenarios, the economic benefit to New York remains positive and would likely be significant.

11. **Cost of Facilitated SDM.** Stout understands that there is an expected one-time cost of $7,000 per person using facilitated SDM in New York. These costs are for training facilitators, developing materials for facilitators to use in their work with Decision-Makers and their supporters, and providing mentors for all facilitators. The one-time per person cost of $7,000 equates to an annual cost of approximately $3.5 million for 500 Decision-Makers each year. Depending on possible variations to future regulations governing the use of facilitated SDM, it is conceivable that facilitation services could be made available more than once in a Decision-Maker's life, however, given the low likelihood that most

[3] Ibid.

decision-makers would be in need of additional facilitation services after initial facilitation was complete, these costs would be negligible.

12. **Benefits of Facilitated SDM.** Stout's estimate of the economic benefits realized by New York through facilitated SDM and legally recognized SDMAs are likely significantly understated. Included in the calculation are benefits of facilitated SDM that are quantifiable and reasonably reliable with available data. However, if PWDD experienced more empowerment, autonomy, self-determination, and the dignity of risk, New York would enjoy many benefits that are not at this time reliably quantifiable and therefore are not included in Stout's calculations. The benefits that would be enjoyed by New York include, but are not limited to:

    - A reduction, over time, of the number of guardianship cases filed resulting in improved use of New York court resources;
    - Increased self-determination, independence, empowerment, inclusion, and dignity (including the dignity of risk) for PWDD, and associated reduction in the use of many Medicaid and state-funded services;
    - Increased quality of life for PWDD;
    - Increased wages and gainful employment opportunities for PWDD;
    - Increased likelihood of being enrolled in formal education;
    - Decreased physical health expenditures and usage of emergency room services;
    - A reduction in the administrative costs and use of resources associated with health care providers and banking institutions, for example, attempting to determine if a person with IDD has capacity to make a decision;
    - A reduction in the number of PWDD interacting with law enforcement, incarceration costs for PWDD, other criminal system costs necessary for adjudicating a case, and the likelihood of recidivism; and
    - Increased likelihood of successful re-entry following incarceration.

13. **PWDD in New York.** In 2019, an estimated 126,000 people in New York were served by the Office for People with Developmental Disabilities (OPWDD).[4] Approximately 63% of people served were male, and 37% were female, which is consistent with the prevalence of intellectual or developmental disabilities (IDD) by gender in the general population.[5] Nearly 80% of people served by OPWDD identified as white (61%) or Black (18%).[6] Figures

[4] https://opwdd.ny.gov/data
[5] Ibid.
[6] Ibid.

1 and 2 show the reported genders and ethnicities of people receiving OPWDD services in 2019, respectively.

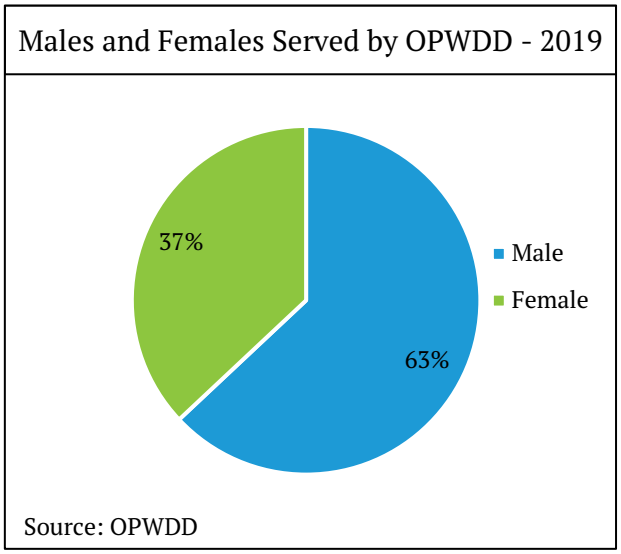

Figure 1

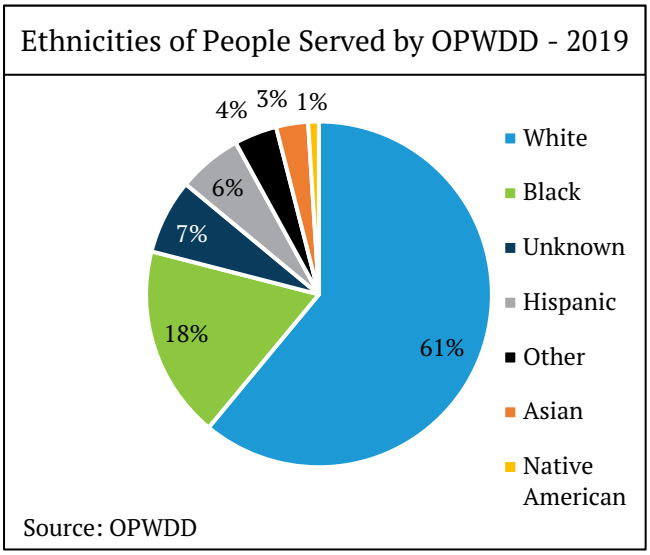

Figure 2

14. People living with IDD may have multiple diagnoses. For example, a person with a primary diagnosis of an intellectual disability may also have a secondary diagnosis of cerebral palsy. Figure 3 shows the people receiving OPWDD Medicaid services by primary diagnosis in 2019.

People Receiving Medicaid Services by Primary Diagnosis - 2019		
Primary Diagnosis	**People**	**Percent**
Intellectual Disability - Mild	42,320	39.4%
Autism Spectrum Disorder	24,915	23.2%
Intellectual Disability - Moderate	11,260	10.5%
Intellectual Disability - Profound	5,737	5.3%
Intellectual Disability - Severe	5,450	5.1%
Cerebral Palsy	4,401	4.1%
Other Neurological Impairments	4,351	4.0%
Intellectual Disability - Unspecified	4,221	3.9%
Unknown / Unidentified*	3,508	3.3%
Epilepsy / Seizure Disorder	1,240	1.2%
Other Developmental Disorders / Delays	139	0.1%
Total	**107,542**	

Source: OPWDD
*Individuals visited an Article 16 clinic to determine whether a developmental disability diagnosis was present.

Figure 3

15. In 2019, more than 60% of people served by OPWDD were adults between 21 and 64 years old.[7] This group of people accounted for nearly 80% of OPWDD Medicaid payments – approximately $6.2 billion.[8] Of all people served by OPWDD, approximately 95% were enrolled in Medicaid – the federal- and state-funded program assisting with health care costs for people with low incomes.[9] In 2019, Medicaid payments for services and supports administered by OPWDD totaled more than $8 billion.[10]

16. OPWDD Medicaid services are paid for either on a fee-for-service basis or through a managed care arrangement.[11] In the fee-for-service model, separate payments are made to providers for each service delivered to a person.[12] In the managed care model, a set monthly payment is paid to an insurance company that then manages and pays for the care.[13] In

[7] https://opwdd.ny.gov/people-receiving-opwddd-medicaid-services#age-group
[8] Ibid.
[9] Ibid.
[10] Ibid.
[11] https://opwdd.ny.gov/understanding-primary-diagnosis
[12] Ibid.
[13] Ibid.

2019, fee-for-service payments accounted for approximately 98% of OPWDD Medicaid payments.

17. More than 80% of OPWDD Medicaid payments in 2019 were for either OPWDD certified housing (60%) or day and employment services (22%). Figure 4 shows the Medicaid fee-for-service by payments by OPWDD service in 2019.

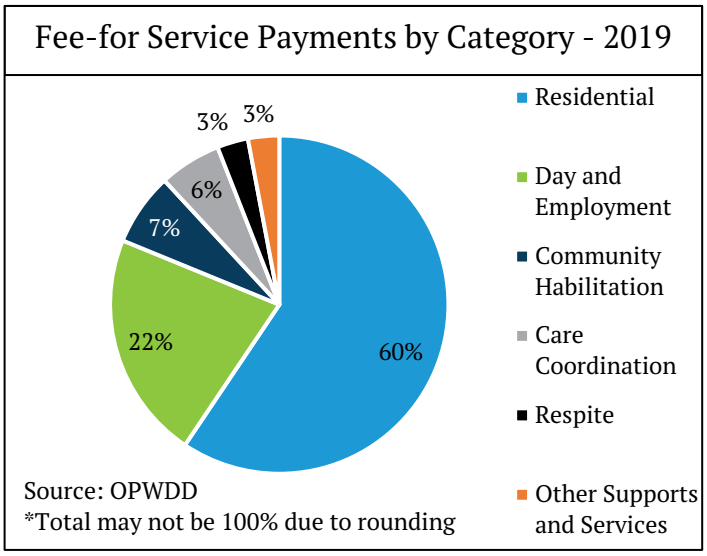

Figure 4

18. **Home and Community Based Services Waivers.** A critical fee-for-service program for people with IDD is Medicaid's Home and Community Based Services (HCBS) waiver. Authorized by Section 1915 of the Social Security Act, HCBS waivers allow states to waive certain Medicaid program requirements, enabling them to provide care for people who prefer to receive services and supports in their home or community rather than in an institutional setting.[14] Nearly all states and DC offer services paid for by HCBS waivers.[15] There are currently more than 300 HCBS waiver programs nationwide.[16]

19. In 2019, OPWDD provided HCBS waiver services totaling approximately $6.4 billion to approximately 86,000 individuals throughout New York. The three service types with the highest Medicaid HCBS waiver spending were:

    - Residential Habilitation – Supervised Model: $3.8 billion;

[14] Home & Community-Based Services 1915(c). Medicaid.gov.
[15] Ibid.
[16] Ibid.

- Day Habilitation: $1.4 billion; and
- Community Habilitation: $520 million.[17]

20. Two key requirements of HCBS programs are that the programs must: (1) demonstrate that providing services in homes or community settings will not cost more than providing the services in an institutional setting; and (2) ensure that the services are individualized and follow a person-centered plan of care.[18] An expectation of HCBS waiver services is that services are directed by the people receiving them and center on their needs, preferences, and goals.[19] One HCBS waiver service modality that states may consider is supported decision-making (SDM).

[17] https://opwdd.ny.gov/services-funded-fee-service-medicaid-2019#home-waiver-services
[18] Home & Community-Based Services 1915(c). Medicaid.gov.
[19] "Making Self-Direction A Reality: Using Individual Budgets to Promote Choice, Control, and Equity." Human Services Research Institute. 2019.

Section III
SDM, SDM Facilitation, and SDMAs

Introduction

21. Supported decision-making (SDM) is an emerging practice by which people with developmental disabilities (PWDD) can make their own decisions with the support of trusted people in their lives. SDM can and does occur informally and is used every day by people who seek support from trusted family and friends when making decisions. However, more recently a more formal process has been developed that leads to written agreements between PWDD, called "Decision-Makers," and their supporters. The result of this facilitated process is a Supported Decision-Making Agreement (SDMA). These agreements detail what areas Decision-Makers want assistance with, what types of supports they want, from whom they want the support, and how they want the support to be given.[20]

22. SDMA legislation, such as that just passed and signed in New York[21], grants legal recognition to decisions made by PWDD utilizing their SDMAs and requires third-parties (e.g., health care professionals, financial institutions, landlords, etc.) who may have otherwise questioned their capacity and refused goods or services, to accept their decisions on the same basis as all others. SDMA legislation incentivizes the use of facilitated SDM, including as a less restrictive alternative to guardianship.[22]

SDM and Guardianship

23. A significant reason for increased interest in SDM in recent years is recognition that it is a "less restrictive alternative" to guardianship.[23] Guardianship is the legal process by which a court removes a person's power and ability to make their own decisions and gives that power to another person – the guardian[24]. New York has two separate guardianship laws: Mental Hygiene Law Art. 81 (Art. 81) and Surrogates Court Procedure Act Art. 17-A (Art. 17-A). The scope of Art. 81 includes anyone who may be unable to provide for their personal needs and/or property management but is used primarily for adults who have "lost" capacity through a stroke or dementia, for example. Art. 17-A, which applies only to PWDD, was enacted in 1969 and has remained essentially unchanged, even as society's

[20] Glen, Kristin Booth. "Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project." 39 Cardozo Law Review 495. 2017.
[21] NY Mental Hygeine Law Article 82, signed by the Governor July 26, 2022, 2022 N.Y. ALS 481, 2022 N.Y. Laws 481, 2022 N.Y. Ch. 481, 2022 N.Y. SB 7107 Chaptered.

[22] Constanzo, Cathy E. "Supported Decision – Making: Lessons From Pilot Projects", 72 Syracuse L. Rev. 99. 2022.
[23] American Bar Association Resolution 113. 2017. Autonomy, Decision-Making and Guardianship, Joint Position Statement of AIDD and The Arc. 2016.
[24] Diller, Rebekah. "Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making", 43 Fordham Urb. L.J. 495. 2016

view of people with disabilities of many types has changed dramatically, particularly with the passing of laws like the Americans with Disabilities Act (ADA) in 1990, the Intellectual Disabilities Education Act (IDEA) in 1975, and the Intellectual Disabilities Education Improvement Act (IDEIA) in 2004. Society has come to appreciate that intellectual and developmental disabilities are not static conditions.[25] PWDD can and do learn and grow over time given adequate supports, and can live self-determined, autonomous, inclusive lives in their communities.[26]

24. The National Council on Disability (NCD) has argued that guardianship hinders this growth and community inclusion, and the lack of autonomy and self-determination resulting from guardianship often has deleterious results on physical and mental health.[27] Yet, as the NCD and others have repeatedly pointed out parents are routinely and repeatedly told by schools, health care providers and others, that they should obtain guardianship over their young adult children when they reach age 18. The NCD refers to as the "school to guardianship pipeline".[28] In 2019 alone, there were more than 17,000 Art. 17-A guardianship filings in New York.[29]

25. The Constitution and settled New York law require that in order to deprive a person of their liberty or property to "protect" them – the justification for guardianship – there must be no less restrictive means to achieve that goal.[30] In the last several years, well-established organizations including, but not limited to, the American Bar Association, the United States Administration for Community Living, the Uniform Law Commission, the National Council on Disability, the American Association of Intellectual and Developmental Disabilities, and the Arc of the United States, have all recognized and encouraged the use of SDM as a "less restrictive alternative" to guardianship.[31] Since 2012,

[25] Andreasian, Karen et al. "Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities." 18 CUNY Law Review 287. 2015.
[26] "Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities." National Council on Disability. 2019.
[27] "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities." National Council on Disability. March 22, 2018.
[28] Ibid.
[29] It is not possible to determine how many of these filings constituted new Art. 17-A petitions from available data.
[30] Kesselbrenner v. Anonymous, 31 N.Y. 161.165 (1973); Manhattan Psychiatric Center v. Anonymous, 285 A.D. 2d 189, 197-98 (1st Dept. 2001)
[31] "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities." National Council on Disability. March 22, 2018.

many New York Courts have denied guardianships or removed previously imposed guardianships where SDM systems were in place.[32]

26. There is also an argument that the Americans with Disabilities Act (ADA) provides for the use of SDM as an alternative to guardianship.[33] It requires public and private entities to provide reasonable accommodations so that people with disabilities can participate in society on an equal basis with others, and scholars have argued that facilitated SDM is an accommodation necessary to permit PWDD to live more inclusive lives than are possible under the restrictions of guardianship.[34] The influential Fourth National Guardianship Summit has recently called on the Justice Department to recognize SDM as a "reasonable accommodation" under the ADA.[35]

27. SDM is not only about avoiding guardianship, it is a critical aspect of ensuring that PWDD have the same right to exercise legal capacity—that is, to have their decisions legally recognized– as other people. This right to legal capacity is derived from Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which recognizes that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."[36] Rather than denying legal capacity to PWDD, Article 12 of the CRPD urges nations to "provide access by persons with disabilities to the support they may require in exercising their legal capacity."[37] This is where SDM comes from, and SDMAs are the necessary component to legislation that requires third parties, both public and private, to respect and honor the decisions of PWDD, unless certain statutory exceptions apply. Without SDMA legislation, the inability of PWDDs to enter into contracts, for example, for housing and employment, not only reduce community inclusion, but also impact the fiscal impact of a marginalized group that it is instead forced to depend on state-provided services.The recent passage of SDMA legislation in New York is intended

[32] Guardianship of Dameris L., 38 Misc. 3d 570 (Surr. Ct., N.Y. Co. 2012) (holding that a "support network" made a guardianship unnecessary and citing Art. 12 of the CRPD); In re D.D., 50 Misc. 3d 666, 677, 19 N.Y.S.3d 867 (Sur. Ct., Kings Co. 2015) (rejecting guardianship petition where individual had a Supported Decision-Making network for 11 years); In re Guardian for Michelle M., 52 Misc. 3d 1211(A), 41 N.Y.S.3d 719 (Sur.Ct. Kings Co. 2016) ("The appropriate legal standard is not whether the petitioners can make better decisions than Michelle, it is whether or not Michelle has the capacity to make decisions for herself, albeit with supportive services.").
[33] Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–213 (2012).
[34] Salzman, Leslie. "Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act." University of Colorado Law Review. 2010.
[35] "Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability, Recommendations Adopted by Summit Delegates." http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability/ May, 2021
[36] United Nations Convention on the Rights of Persons with Disabilities. Article 12(2).
[37] United Nations Convention on the Rights of Persons with Disabilities. Article 12(3).

and expected to prevent third party discrimination against PWDDs based on their disability.

SDMNY and SDM Facilitation

28. Although PWDD may informally use others to support them when making decisions, facilitated SDM involves a process aimed at ensuring that Decision-Makers understand what goes into making a decision, how to access and utilize support, that decisions are actually being made by the PWDD, and that supporters are not reverting to familiar practices of paternalism, protection, or substitute decision-making. New York has been at the forefront of exploring and developing effective SDM facilitation to make SDM a tool for promoting self-determination and autonomy for PWDD and achieving the non-monetary and monetary benefits of SDM and SDMAs.[38]

29. In 2016, the New York State Developmental Disabilities Planning Council (DDPC) awarded a five-year, $1.5 million grant to Supported Decision-Making New York (SDMNY) a consortium of Hunter College/City University of New York, the New York Alliance for Inclusion and Innovation, and the Arc Westchester to educate stakeholders and the public about SDM and to pilot the use of SDM to divert PWDD at risk of guardianship and restore rights to those already subject to guardianship. A sixth year, necessitated by COVID-19 related delays, was funded by The Ford and Taft Foundations and The FAR Fund. During those six years, SDMNY has developed a three-phase facilitation process for PWDD (called "Decision-Makers") and their supporters using volunteer facilitators. SDMNY has enrolled more than 150 racially, ethnically, and geographically diverse Decision-Makers and trained more than 200 facilitators, making it the longest and largest SDM pilot project in the United States. Learnings from SDMNY have been independently evaluated[39] and published in professional journals.[40] The SDMNY pilot project was preceded by a smaller, pilot project in Massachusetts (the CPR-Nonotuck pilot project) that used a similar facilitation model and has been well evaluated by the Human Services Research Initiative (HSRI).[41]

30. SDMNY leadership has been invited to present its model at national conferences and meetings including the National Resource Center on Supported Decision-Making, the National Disability Rights Network, the Asperger/Autism Network, the U. S. Department

[38] Constanzo, Cathy E. "Supported Decision – Making: Lessons From Pilot Projects", 72 Syracuse L. Rev. 99. 2022.
[39] Pell, Elizabeth. "Supported Decision-Making New York: Evaluation Report of an Intentional Pilot." Hunter College/The Research Foundation CUNY. 2019. https://sdmny.org/resource-type/evaluations/
[40] Glen, Kristin Booth. "Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project." 13 Albany Government Law Review 94. May 2020.
[41] Pell, Elizabeth and Mulkern, Virginia. "Supported Decision Making Pilot: A Collaborative Approach, Pilot Evaluation Year 1." The Human Services Research Institute. 2015.

of Justice Civil Rights Division, and internationally in Iceland and the United Kingdom. SDMNY has trained facilitators and worked with the Protection and Advocacy Agency in Maine to develop an SDM program for the state and is currently collaborating with groups in Pennsylvania to introduce SDM facilitation. In New York, SDMNY has presented at, inter alia, the annual meeting of the New York State Bar Association, the Adult Abuse Training Institute, the New York State Surrogate's Association, the New York State Judicial Institute, Parent-to-Parent New York, and the Self Advocacy Association of New York State.

31. The SDMNY facilitation model has been transformative for both Decision-Makers and their supporters.[42] It has also been effective in diverting PWDD from guardianship. Parents of transition age youth have welcomed an alternative to guardianship that will enable their loved ones to retain their legal rights, build self-determination, and create a network of support that can be expected to continue even after parents have passed.[43] Families that have already begun guardianship proceedings have put them "on hold" while SDMNY facilitation was explored, and have subsequently discontinued those proceedings with confidence that they had found a better, less restrictive alternative.[44] Many families, however, expressed concern that, unless decisions made pursuant to SDMAs were "legalized," they might find themselves in situations where third parties refuse to honor them, and guardianship would still be necessary.[45] The recent passage of SDMA legislation is expected to significantly incentivize families who would otherwise have sought guardianship to use SDM facilitation instead.[46]

SDMA Legislation: Impact on PWDD and Their Families

32. The DDPC grant also charged SDMNY with developing an evidentiary basis for potential SDMA legislation in New York. Over an 18-month period, in an iterative process drawing on its extensive Advisory Council and stakeholder focus groups, SDMNY created "Principles for SDMA Legislation"[47] based on its learning over the five-year grant period. On March 1, 2021 the Governor's Office sent a "departmental" SDMA bill drafted by the New York State Office for People With Developmental Disabilities (OPWDD) that included

[42] Constanzo, Cathy E. "Supported Decision – Making: Lessons From Pilot Projects", 72 Syracuse L. Rev. 99. 2022
[43] Ibid. And see parents confirming at https://sdmny.org/resource-type/videos/
[44] See e.g. https://vimeo.com/580036697
[45] Pell, Elizabeth. "Supported Decision-Making New York: Evaluation Report of an Intentional Pilot." Hunter College/The Research Foundation CUNY. 2019.
[46] Glen, Kristin Booth. "Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project."13 Albany Government Law Review94, May 2020
[47] "Introduction: Supported Decision-Making and Supported Decision-Making Agreements." SDMNY Website. N.d.
[48] NY LEGIS 481 (2022), 2022 Sess. Law News of N.Y. Ch. 481 (S. 7107-B) (McKinney's)

many of those Principles, and includes a requirement that, in order to require third party recognition of decisions made pursuant to an SDMA, the SDMA should be made through a facilitation process to be further described in regulations to be promulgated by OPWDD. Although the bill passed the State Senate unanimously, the session ended before the bill could be considered by the Assembly. With several non-substantive technical amendments the bill was reintroduced in the 2022 session. It passed both houses and was signed by Governor Kathy Hochul on July 26, 2022, the anniversary of the Americans with Disabilities Act.[48] New York is the first jurisdiction to have tied legislative recogntion of decisions made with SDMAs to a meaningful process of education/facilitation for both Decision-Makers and their Supporters, consistent with the National Council on Disability Report, which found that SDMA legislation without training (or facilitation) is insufficient.[48]

33. Passage of New York's SDMA legislation will likely have significant impacts on PWDD and the systems with which they and their parents interact. The number of guardianship filings is almost certain to decrease, and many young adults with developmental disabilities will retain all their legal and civil rights. The legislation will incentivize the facilitation process required for SDMAs that assures legal recognition of decisions by PWDD, which will give them the dignity of risk and increase self-determination, autonomy, and inclusion, with many corresponding benefits. Research has shown that PWDD who are more self-determined and autonomous are healthier, use fewer services, are more likely to be employed, and are more likely to live in the community rather than in costly certified residences.[49,50]

SDMA Legislation: Impact on Public and Private Parties

34. The capacity of PWDD to make decisions on their own is often questioned by third parties, such as, for example, medical professionals, banks, and landlords.[51] Legal recognition of decisions made by PWDD with SDMAs will mean that third parties will be obligated in almost all cases to accept the decisions of PWDD made in accordance with their SDMA, regardless of the third party's belief that an individual PWDD may lack the requisite capacity.

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[48] "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination." National Council on Disability. March 2018.
[49] Agran, Martin. "Ensuring Quality Education to Promote Transition: A Summary of Existing Studies." Inclusion. 2018.
[50] Friedman, Carli. "Choosing Home: The Impact of Choosing Where to Live on People With Intellectual and Developmental Disabilities' Emergency Department Utilization." 2021.
[84] "Final Results from our Supported Decision-Making Survey." National Resource Center for Supported Decision-Making. April 2016.

35. A common current example of this kind of denial occurs in situations when PWDD need medical treatment, and health care professionals are uncertain if they can give informed consent.[52] Even where the law provides alternatives, as in the Family Health Care Decisions Act (FHCDA),[53] the surrogate decision-making that it permits cannot occur until there has been a formal process for determining incapacity, and then a search for someone who comes within the ranked categories of relationship in the law who is willing to make the decision in question. A necessary medical treatment may have been unnecessarily, and perhaps dangerously, delayed, and a considerable amount of health care providers' valuable time wasted in the process. If an SDMA were in place, the health care provider would be required to honor the agreement – and the decisions of the PWDD – and be relieved of any possible liability based on the PWDD's alleged incapacity.[54] There may also be fiscal benefits to eliminating the considerable time spent by health care providers trying to identify surrogates to make medical decisions for PWDD. For example, if there are 100 PWDD every year with SDMAs who require a medical decision to be made, and health care providers finding someone who they believe can make a decision for each of them would take 5 hours, then SDMA legislation would save 500 hours of health care provider time. If the value of the health care provider's time is $200 per hour (salary, benefits, etc.), then this time savings could be considered a social benefit with approximately $100,000 in value annually. The same may be true of banking and financial institutions, and others who are using valuable resources trying to ensure that a person has capacity to make a decision. Such inefficiencies would be eliminated by SDMAs.

36. Together, SDM facilitation as developed through New York's five-year investment in the SDMNY pilot project, and now legally recognized SDMAs should result in substantial monetary and non-monetary benefits to PWDD, their families, New York State, and third parties including, but not limited to, healthcare providers and financial institutions.

[52] "The Case for Legal Recognition of SDMAs: Parents Concerned About Third Party Refusals." SDMNY Video. https://sdmny.org/resources/the-case-for-legal-recognition-of-sdmas-parents-concerned-about-third-party-refusals/

[53] N.Y. Pub. Health Law Sections 2994-a-2994-u; https://sdmny.org/resources/the-case-for-legal-recognition-of-sdmas-parents-concerned-about-third-party-refusals/

[54] Glen, Kristin Booth. "Introducing a "New" Human Right: Learning From Others, Bringing Legal Capacity Home." 49 Columbia Journal of Human Rights 1. Spring 2018.

Section IV
Estimated Benefits and Costs of Facilitated SDM and Legally Recognized SDMAs

37. The economic or fiscal benefits of facilitated SDM and SDMA legislation can be categorized as both quantifiable and non-quantifiable. Quantifiable benefits are benefits that can be measured using available, reliable, and reasonable data. Non-quantifiable benefits are benefits that exist but cannot be measured at this time because either there is currently insufficient data or because the benefits are qualitative in nature (e.g., increased empowerment, autonomy, self-confidence, the dignity of risk) and have not yet been quantitatively connected to fiscal benefits.

38. Facilitated SDM and legally recognized SDMAs are relatively new so there is not yet sufficient data to compare outcomes (e.g., housing, health care, employment / employability) between PWDD with legally recognized SDMAs using facilitated SDM and those without.[55] To date, there have been only two studies (in Bulgaria and Australia, where pilot projects began in 2012) of how SDM facilitation directly results in cost savings to governments.[56] In the absence of direct data on the impact of SDM and SDMAs in the US and especially in New York,[57] we believe it is reasonable to extrapolate the findings from those studies and apply them to the US/NYS context.

Cost of Supported Decision-Making Facilitation Services

39. As SDMNY has developed and refined its service delivery model, it has been able to use its now considerable experience to estimate the costs of expanding FSDM statewide using a model with a central Facilitation Training, Research and Education Center (FTREC) that would provide uniform training to facilitators who would come from, and be paid by, a variety of sources, including Medicaid waiver funds through Self-Direction, and the private bar, as well as unpaid volunteers, and graduate professional students who would be trained in, and provide facilitation as part of their fieldwork requirements.[58] Extensive facilitator training materials have already been created and used successfully, but, over time, at least

[55] Although 15 states and the District of Columbia have enacted SDMA statues, there has been no evaluation, research, or data collection regarding the consequences or outcomes of that legislation or the use of legally recognized SDMAs. The financial benefits of SDM have also not been researched or quantified.
[56] The SDMNY pilot drew on the experiences of the Bulgarian and Australian SDM pilots, among others, in creating its facilitation model.
[57] The SDMNY project was to have been completed in March 2021, but because of COVID-19, the planned fifth year (March 2020-March 2021) was essentially lost. The pilot, with additional funding from the Ford Foundation, the FAR Fund, and the Taft Foundation, was completed in March 2022. In that same month, SDMNY received a new, $4million grant from OPWDD to, inter alia, develop and pilot a scalable model for the FTREC.
[58] Glen, Kristin Booth. "Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project." 13 Albany Government Law Review 94. May 2020.

some revisions, including changes based on new research into SDM, may be necessary and would be generated by the FTREC.

40. SDMNY has demonstrated the importance of high-quality mentoring of facilitators to the integrity, consistency and accountability of the facilitation process; all mentoring would be done from the central FTREC, which would also produce and supply materials for use by facilitators, building on those already developed by SDMNY. SDMNY has been able to measure and document the average number of facilitator meetings necessary to reach an SDMA, and the amount of time mentors spend over the course of an individual facilitation, as well as the costs of overseeing the work of the mentors. Regional coordinators would be responsible for aiding PWDD who sought FSDM with trained facilitators, connecting the facilitators with mentors from the FTREC, maintaining records and engaging in problem-solving as necessary.

41. SDMNY has estimated the costs of a statewide model serving 500 PWDD a year at approximately $3.5 million, or approximately $7,000, per PWDD, as shown below. If demand increased, overall cost would increase as well, while per person cost might decrease slightly, as the primary cost is for mentoring, which is a constant for each additional DM.

42. The model SDMNY developed and piloted conceives of the SDM facilitation process as a one-time event/expense, creating a structure through which PWDD and their supporters, who are expected to change over time, can engage in a process of decision-making support.

43. The SDMNY facilitation model currently in use includes information on changing the SDMA as needed, including adding or deleting supporters, changing areas of support, and/or the kinds of support that may be desired. It has also recognized that, as new supporters are added, they will need information to enable them to fulfill their roles with fealty to the principles of SDM, but that it is obviously impractical to require an entire new round of facilitation when a Decision-Maker chooses a new supporter or supporters. Accordingly, SDMNY is currently developing a written Supporters' Guide and video training materials that can be made available both to new supporters, and those who have already engaged in the facilitation process, but who may need some capacity-building or strengthening to maintain their commitment to the Decision-Maker's autonomy and self-determination.

44. The proposed model does not anticipate that Decision-Makers who have completed the facilitation process and signed their SDMAs will require and direct additional services, but the relatively modest research and education components of the FTREC should be

adequate to provide written and distance learning materials, including, and built upon those already developed by SDMNY, to meet the needs of Decision-Makers and supporters going forward.

SDM Sustainability Budget	Persons	Regions	Base Salary	Fringe	
Central Entity					
Personnel					
Program Director	1	1	$ 125,000.00	1.28	$ 160,000.00
Program Coordinator	1	1	$ 90,000.00	1.28	$ 115,200.00
Financial Officer	1	1	$ 70,000.00	1.28	$ 89,600.00
Program Auditor	1	1	$ 70,000.00	1.28	$ 89,600.00
Master Trainers	2	1	$ 70,000.00	1.28	$ 179,200.00
Training Assistant	1	1	$ 50,000.00	1.28	$ 64,000.00
Communications Officer	0.5	1	$ 60,000.00	1.28	$ 38,400.00
Mentors (p/t, field-based)	5	5	$ 40,000.00	1.00	$ 1,000,000.00
Office Assistant	0.5	1	$ 30,000.00	1.28	$ 19,200.00
Direct Costs					
Printing	1	1	$ 5,000.00	1.00	$ 5,000.00
Website	1	1	$ 5,000.00	1.00	$ 5,000.00
Travel	2	5	$ 1,000.00	1.00	$ 10,000.00
Indirect					
Administrative				10%	$ 177,520.00
Field Entities					
Site Coordinators	1	5	$ 70,000.00	1.28	$ 448,000.00
Site Coordinator's Assistant	1	5	$ 50,000.00	1.28	$ 320,000.00
Site Coordination Overhead				10%	$ 768,000.00
					$ 3,488,720.00

Study of Economic Benefits of Facilitated SDM in Bulgaria

45. Bulgaria began a pilot project on SDM, utilizing a facilitation process, in 2012, and commissioned a rigorous and thorough cost-benefit analysis in 2014 (the Bulgarian study) prepared by De Pasarel Bulgaria (Radoslava Lalcheva and Miryana Malamin) in partnership with the Bulgarian Center for Not-for-Profit Law and acknowledging the contributions of Dr. Michael Bach (Institute for Research and Development on Inclusion and Society, Canada) and Freddy Wools (De Pasarel the Netherlands). The Bulgarian study was "the first attempt to provide evidence that SDM as alternative to guardianship system is beneficial to both the persons with ID and MHP and the society not only in terms of non-monetized effect – increased QL and consistency [with] UNCRPD, but also from [a] merely

economic perspective." The study used various research instruments and techniques, as well as client interviews and questionnaires in order to develop a reliable estimate of monetary and non-monetary impacts associated with SDM.

46. The Bulgarian study involved 53 people with mental health challenges or IDD who were either under guardianship or participating in pilot SDM programs utilizing a facilitation process with trained facilitators who worked with Decision-Makers and their supporters.[59,60] The study population of 53 people was segmented into three categories: participants in the SDM pilot projects who were using facilitated supported decision making for at least six months (36 people); people living with IDD who were under guardianship and who lived in the community (6); and people living with IDD who were under guardianship and who lived in specialized institutions (11).[61] The researchers focused on two areas of impact: non-monetized benefits (e.g., quality of life measures, independent living, community inclusion, and equal recognition under the law) and monetized benefits (e.g., areas of cost savings).

47. For the non-monetized benefits, the researchers used two instruments for measuring the impact of SDM on quality of life: the Personal Outcome Scale (POS) and the World Health Organization Quality of Life Questionnaire (WHOQoL), which was specifically designed for PWDD.[62] The POS was developed by researchers in Belgium and is a conceptual four-point framework that asks participants about their personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being. The POS is considered a validated means for measuring an individual's quality of life.[63] The WHOQoL was created through a 15-country collaborative effort and focuses on areas of health, lifestyle, living standards, mental health, and welfare.[64]

48. For the monetized benefits, the researchers used publicly available national data and data from the SDM pilot projects. The publicly available national data included information from official government agencies, such as the Agency for Social Assistance, the Council

[59] "Cost Benefit Analysis of Supported Decision-Making." Bulgarian Center for Not-for-Profit-Law. 2014.
[60] As noted in the Bulgarian Study, "The Bulgarian Center for Not-for-Profit Law (BCNL) was founded in July 2001 and is incorporated as a public-benefit foundation in the Central Register at the Ministry of Justice. BCNL's mission is to provide support for the drafting and implementation of legislation and policies aiming to advance civil society, civil participation and good governance in Bulgaria."
[61] Ibid.
[62] Ibid.
[63] Ibid.
[64] Ibid.

of Ministers, the National Center for Community Health and Analysis, and the National Health Insurance Fund. For the quantification of monetized benefits, the researchers sought to answer three questions:

- Does facilitated SDM reduce the need for or intensity of social services (e.g., institutionalized living environments, consultative services, day care services, ambulatory supports, and homecare)?
- Does facilitated SDM reduce the need for or intensity of health care services?
- Does facilitated SDM increase employment?

49. The researchers found that the monetized benefits of facilitated SDM quantified in the three areas above significantly outweighed the cost of facilitated SDM, leading to a positive return on investment. Furthermore, the Bulgaria study notes that:

> "financial benefits should only serve as an additional secondary argument for making policy choices regarding the necessity of introducing mechanisms for SDM. The non-monetized benefits that cannot be expressed in financial terms have in the case of SDM much bigger value. Quality of life, respect for human rights, independent living and inclusion in the community for PWDD are 'priceless' benefits…"[65]

50. Due to the current lack of facilitated SDM or SDMA impact assessments in the United States, Stout has relied on observations from the Bulgarian study in combination with impact assessments of other supports for PWDD. The Bulgarian study quantifies cost savings in many systems (e.g., housing, health care, employment) that operate reasonably similarly to systems in the United States and provide a reasonable basis for Stout's calculations, particularly in combination with other identified impact assessments. The impact assessments of other supports for PWDD measure the impact of supports that increased independent decision-making, empowerment, self-determination, inclusion in society, self-confidence, and autonomy – all of which can be attributed to facilitated SDM and SDMAs. As evidenced by the Bulgarian study, Stout expects that these qualitative impacts will lead to reductions in social services costs and health care costs and an increase in employment for PWDD, as well as reductions in time spent by other systems determining whether a person with developmental disabilities has adequate capacity and, if not, what to do (such as healthcare and financial services).

[65] Ibid.

Potential Value of Decreased Guardianship Filings in Surrogates Court

51. In 2015, Texas was the first state to pass an SDMA statute, with one of its explicit purposes to control the cost of guardianships in the Texas court system.[66] Since enactment of the statute, guardianship filings have decreased[67], a result equally likely to occur in New York now that SDMA legislation has been enacted.

52. In 2019, there were 16,779 guardianship filings statewide in Surrogate's Court.[68] Specific budget information to calculate the precise cost to New York of Article 17-A guardianship proceedings is not available. In larger counties, there may be a department devoted to guardianship with one or more full time employees and proportional costs associated with administration, technology infrastructure, training, supplies, facilities, and maintenance.

53. Using the Surrogate's Court budget, non-capital expenses can be allocated on a per guardianship filing basis. If there are fewer guardianship filings in New York, Surrogate's Court resources may be used more efficiently, effectively, or reallocated to other under-resourced areas.

54. In 2019, there were approximately 141,000 total filings in Surrogate's Court, of which approximately 17,000 (12%) were related to guardianships.[69] There were approximately 118,000 total dispositions, of which approximately 9,000 (8%) were related to guardianships.[70] The 2019 Surrogate's Courts budget was approximately $53.8 million.[71] Based on the number of filings, the pro-rata budget allocation associated with guardianships was approximately $6.4 million. Based on the number of dispositions, the pro-rata budget allocation was approximately $4.3 million.

55. If facilitated SDM could decrease total guardianship filings by 25%, and assuming a pro-rata budget impact, the cost of guardianship filings to the courts could decrease from $6.4 million to $4.9 million. If based on the number of dispositions, the cost of guardianship

[66] Eliana J. Theodorou, "Supported Decision-Making in the Lone Star State", 93 NYU Law Review 973, 2018.
[67] The State of Texas, Office of Court Administration. "Guardianship Reform: Protecting the Elderly and Incapacitated." 2019 available at https://www.txcourts.gov/media/1443314/texasguardianship-reform_jan-2019.pdf
[68] New York State Unified Court System, 2019 Annual Report,40 (2019) available at https://www.nycourts.gov/legacypdfs/19_UCS-Annual_Report.pdf
[69] Ibid.
[70] Ibid.
[71] New York State Unified Court System Budget Fiscal Year 2019-2020, 25 available at http://ww2.nycourts.gov/sites/default/files/document/files/2018-11/2019-20-JUDICIARY-Budget.pdf

filings to the courts could decrease from $4.3 million to $3.1 million. Thus, such a decrease in guardianship filings could result in resources savings of $1.2 million to $1.5 million which could be reallocated for other valuable activities.

56. These resource savings do not consider Mental Hygiene Legal Services (MHLS), a separate arm of the court system, that provides mandatory representation when a person for whom guardianship[72] is sought resides in a state-funded facility. MHLS may also be assigned as Guardian ad Litem or as counsel when the person resides in the community. If facilitated SDM could decrease guardianship filings, MHLS would realize similar benefits as Surrogate's Court.

57. Although there is not data regarding how many Article 81 guardianships are sought for and imposed on PWDD, anecdotally there has been an increase in the use of this more nuanced statute. Because facilitated SDM would likely be particularly attractive to parents and other petitioners concerned with removing all the rights of PWDD, it is reasonable to expect a reduction in such petitions with similar benefits as those expected from decreasing Article 17-A guardianships. The benefits attributable to decreasing the number of Article 81 guardianships would likely be greater over time because, unlike Article 17-A, Article 81 guardianships require ongoing court-supervised monitoring and review which require court resources.

Fiscal Benefits of Enhancing Self-Determination through Facilitated SDM and SDMAs

58. Facilitated SDM increases delf-determination by enabling PWDD to make their own decisions, including choosing their own services. One study examining the link between PWDD choosing their own services and their quality of life ("the CQL study") showed that self-determined PWDD are almost twice as likely to choose their services as those who are under guardianship.[73]

59. Self-determination can lead not only to a better life for individuals but also significant cost savings to New York. For example, as described in the following paragraphs, maintaining the authority to make one's own decisions with the support of trusted people in one's life means will likely lead PWDD to use fewer services, be less likely to need to live in an

[72] MHLS's obligations are similar in Article 81 and Article 17-A cases. Data for each case type separately does not exist. Article 81 cases are filed and adjudicated in Supreme Court, and Article 17-A cases are filed and adjudicated in Surrogate's Court.

[73] Friedman, Carli and VanPuymbrouck, "The Impacts of People with Disabilities Choosing Their Services on Quality of Life Outcomes." Disability and Health Journal. November 2018.

OPWDD-certified or quasi-institutional setting, be healthier and use fewer resources in the health care system, and be more employable and have better job outcomes.

60. **Decreased use of HCBS Waiver and State Plan Services.** The ability to choose one's own services under Medicaid 1915(c) Home & Community Based Services Waivers (HCBS Waiver services) and New York's 5.07 Comprehensive State Plan for Persons with Disabilities (State Plan services) also has fiscal consequences. One reason for the proliferation of Self-Directed Medicaid Services programs across the states (self-direction) has been the expectation that people using self-direction will make "better" choices, resulting in the use of fewer unnecessary services, and reduced costs to the state and federal Medicaid systems.

61. One study on the cost of savings of PWDD in Michigan using self-direction (the Michigan study) reported a median reduction of 8% in the cost of serving PWDD.[74] The same study found that program savings increased to 14% when expenditures were adjusted for inflation over the same three-year period, with the median public cost per participant declining from $67,322 to $56,778 in inflation-adjusted dollars.[75] The study also found that participants reported they had more and better choices, less professional domination, and an overall higher quality of life.

62. As self-direction increasingly becomes a favored means for delivering services to PWDD, its success largely depends on the ability of recipients to make good choices about the services they actually need and ones that will move them toward greater independence and inclusion, rather than simply accepting the services offered by traditional provider agencies. Facilitated SDM may be the segue to utilizing self-direction in the most productive and cost-effective manner and to ensure PWDD are truly self-directing.

63. Numerous studies have shown the benefits of self-determination for PWDD, and the SDMNY pilot project has demonstrated an effective means of doing so through its three-phase facilitation process. For PWDD, becoming self-determined is a process, often because they are accustomed to being recipients of services. Simply receiving services rather than making decisions about services and other aspects of life has resulted in PWDD missing the experiences that neurotypical adolescents and young adults have in making decisions (good and bad), learning from those experiences, and growing into autonomous

[74] Head, James and Conroy, Michael. "Outcomes of Self-determination in Michigan: Quality and Costs." In Stancliffe and Lakin, Costs and Outcomes of Community Services for People with Intellectual Disabilities. 2005.
[75] Ibid.

adults.[76] The facilitation process is the mechanism for enabling PWDD to become agents in their own lives, and now that SDMA legislation has been enacted, can make community inclusion a realizable goal.

64. Anecdotally, in the SDMNY pilot project, the majority of persons completing facilitated SDM and signing their SDMAs show a considerable increase in self-determination. Extrapolating from the CQL study, almost half of PWDD who use facilitated SDM to avoid guardianship could be expected to become more self-determined. Further extrapolating from the Michigan study, those individuals who became more self-determined could be expected to use between 8% and 14% fewer services. Were the Bulgarian study instead used to extrapolate, approximately 27% of PWDD using facilitated SDM could be expected to see the aforementioned reduction in use of services.[77]

65. **Increased Likelihood of Attaining and Maintaining Independent Living.** In the cost-benefit study of facilitated SDM in Bulgaria, researchers found that more than half of PWDD living in institutionalized settings had sufficient independency skills to live within their communities with less intensive forms of services and with SDM.[78] PWDD are often placed in quasi-institutionalized or institutionalized settings not because of their need for intensive support but because of inadequate alternative living arrangements.[79] Unnecessarily living in institutionalized settings has been shown to decrease independence and self-determination, contribute to worse health outcomes, and increase costs to jurisdictions responsible for funding institutional living.[80] The Autistic Self Advocacy Network recommends that disability rights advocates collaborate with disability-friendly landlords around independent living for PWDD and identifies disability-friendly landlords as key in successfully using SDM for DMs wanting to live independently.[81] Furthermore, an SDMA would create a legally recognized agreement that a landlord may be required to acknowledge without fear of liability.

66. Anecdotal evidence, including from SDMNY and OPWDD, indicates that parents may prematurely and prophylactically place their adult children with DD in congregate settings to ensure they will be settled in if and when the parents are no longer able to care for them.

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[76] "Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities." National Council on Disability. 2019.
[77] "Cost Benefit Analysis of Supported Decision-Making." Bulgarian Center for Not-for-Profit-Law. 2014.
[78] "Cost Benefit Analysis of Supported Decision-Making." Bulgarian Center for Not-for-Profit-Law. 2014.
[79] Ibid.
[80] Ibid.
[81] "ASAN's Invitational Summit on Supported Decision-Making and Transition to the Community: Conclusions and Recommendations." Autistic Self Advocacy Network. 2016.

Facilitated SDM has potential to alleviate this concern, avoiding or delaying entry into congregate care settings like those operated through OPWDD's Residential Habilitation services, by increasing PWDD's self-determination and allowing them to choose alternative independent living arrangements.

67. Research shows that PWDD who are more self-determined are more likely to live independently in the community and are less likely to be placed in congregate settings.[82] In other words, PWDD who are less self-determined and who use substitute decision-making regimes instead of making their own decisions are more likely to be housed in congregate settings, in part due to a lack of choice. People who use independent decision-making, of which facilitated SDM is one form, are more likely to choose to live in the community.[83]

68. Research also shows that over-institutionalization occurs in states with higher-than-average scores of disability prejudice, measured against a national average of prejudice against PWDD. New York is one such state, which is estimated to result in 399 unnecessary institutionalizations per year.[84] One of the widely expected results of facilitated SDM and legislatively recognized SDMAs by PWDD is a decrease in bias and prejudice against them.[85] Over time, and with greater public knowledge about SDM and SDMAs, and the greater self-determination and community inclusion of persons with I/DD using FSDM and SDMAs, New York's disability prejudice score should be expected to decrease, with significant public savings from a decrease in institutionalization, as well as the non-monetary benefits of decreased discrimination against PWDD.

69. Research also shows that PWDD, especially those with dual diagnoses, living in the community are less likely to return to institutions when they have more organizational supports.[86] PWDD who utilized independent decision-making akin to SDM had four times as many community organizational supports that people various forms of guardianship.[87]

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[82] Friedman, Carli. "Organizational Supports to Promote the Community Integration of People with Dual Diagnosis." Intellectual Developmental Disability. 2021.
[83] Friedman, Carli. "Choosing Home: The Impact of Choosing Where to Live on People With Intellectual and Developmental Disabilities' Emergency Department Utilization." 2021.
[84] Friedman, Carli. "The Relationship Between Disability Prejudice and Institutionalization of People With Intellectual and Developmental Disabilities." Intellectual and Developmental Disabilities. 2019.
[85] Ibid.
[86] Friedman, Carli. "Organizational Supports to Promote the Community Integration of People with Dual Diagnosis." Intellectual Developmental Disability. 2021.
[87] Ibid.

70. The closing of the Goldwater Memorial and Coler Hospitals on Roosevelt Island in 2013 provided the opportunity to offer alternative housing and care to residents with I/DD and nursing home residents who were Medicaid beneficiaries.[88] The nursing home patients were transferred to an affordable and accessible building in East Harlem designed to accommodate residents' needs.[89] A 2017 evaluation of the transition found a statistically significant decrease in total and average Medicaid costs, with cost savings related to physician services, clinical services, pharmacy services, lab services, and emergency department services.[90] Qualitatively, evaluators described residents forming neighborly relationships with each other, participating in cultural activities, shopping at local stores, and volunteering in the community.[91]

71. Given the conclusions of the Goldwater-Coler evaluation, the savings associated with reducing unnecessary institutionalization and use of congregate care in favor of lower levels of care in the community, are not only found in the reduction of housing costs.[92] The Goldwater-Coler study provides evidence that when people are not in institutional or quasi-institutional settings, their use of associated non-residential services decreases dramatically, such as those HCBS waiver services referenced above.[93]

72. One significant challenge that PWDD face in attaining independent living is the issue of housing affordability.[94] OPWDD's Individual Supports and Services Housing Subsidy Program (ISS) provides housing vouchers designed to allow income-eligible PWDD to live independently in their community in traditional forms in housing.[95] PWDD with ISS vouchers are expected to contribute approximately 30% of their income towards housing

[88] "East Harlem, New York: Supporting Affordable Living and Health Care as Part of State Medicaid Redesign." Office of Policy Development and Research, U.S. Department of Housing and Urban Development. 2016. https://www.huduser.gov/portal/casestudies/study-05162016-1.html; *See also*, "The Color Coldwater Long Term Acute Care Hospital (LTACH)." New York City Health & Hospitals Corpopration. 2013. https://www.nychealthandhospitals.org/coler/wp-content/uploads/sites/6/2016/08/chna-goldwater-2013.pdf; "Coler-Goldwater's Innovative Volunteer Extended Self-Care Program." New York City Health & Hospitals Corpopration. 2013. http://www.nyc.gov/html/hhc/coler-goldwater/pdf/fohwinter1314-2.pdf.
[89] Ibid.
[90] Dewar, Diane and Polvere, Lauren. "Medicaid Redesign Team Supportive Housing Evaluation: Cost Report 1." New York State Department of Health. May 2017.
[91] "East Harlem, New York: Supporting Affordable Living and Health Care as Part of State Medicaid Redesign." Office of Policy Development and Research, U.S. Department of Housing and Urban Development. 2016.
[92] Ibid.
[93] Ibid.
[94] Schaak, Gina et al. "Price Out: The Housing Crisis for People with Disabilities." Technical Assistance Collaborative, Inc. December 2017.
[95] Ibid.

costs, and the ISS program pays the difference up to a set maximum allowable amount.[96] While it can already be difficult for PWDD to identify housing opportunities that make the ISS subsidy feasible financially, anecdotal evidence indicates that even when housing is found, landlords are hesitant to accept a PWDD's signature on a lease. Facilitated SDM would provide a tool for PWDD to enforce their own decisions related to housing by placing a requirement on landlords to accept the decisions and signatures of PWDD who have utilized a facilitated SDMA.

73. Available information regarding OPWDD's maximum monthly contribution under ISS for a 1-bedroom apartment is $1,324.[97] This monthly contribution is likely lower, given the anecdotal prevalence of PWDD choosing to live with roommates and the variation of housing costs around the state, both of which could reduce the state per person contribution. By contrast, the cost of congregate settings is significantly greater. The most prevalent form of Residential Habilitation service used by over 29,000 PWDD in New York State, is estimated to cost more than $130,000 per person, per year.[98]

74. **Reduced Use of Emergency Department and Improved Health Care Outcomes.** A 2021 exploratory study examining the impact that choice of housing can have on emergency department utilization by PWDD found that decision-making authority was statistically significant in determining emergency department use.[99] The study further found that regardless of the severity of cognitive impairment of the participants, people who made their own choices about where to live and with whom visited emergency departments 74% less than those who did not make their own choice.[100] PWDD who made their own decisions averaged 1.39 ER visits, those under guardianships averaged 2.75 visits, and those who used other forms of substitute decision-making averaged 2.77 visits.[101] Accordingly, were facilitated SDM to be used as means to effectuate independent decision-making, decision-makers could see an average reduction of emergency department utilization by as much as

[96] "Right at Home: Supports at Home and Help with Housing." New York State Office for People With Developmental Disabilities. 2020. https://opwdd.ny.gov/system/files/documents/2020/03/032_right-at-home-housing-brochures_342020.pdf
[97] Bae, Young Seh. "NYS Disability Resource Navigator for Preparing Adult Life." Community Inclusion and Development Alliance. 2020.
[98] https://opwdd.ny.gov/data/services-funded-fee-service-medicaid-2020#comprehensive-hcbs-waiver-services
[99] Friedman, Carli. "Choosing Home: The Impact of Choosing Where to Live on People With Intellectual and Developmental Disabilities' Emergency Department Utilization." 2021.
[100] Ibid.
[101] Ibid.

50% compared to those under guardianship and other forms of substitute decision-making.

75. Findings from a 2010 interview-style study of people who were self-directing their health care indicated that empowering people to make decisions about their health care decreased use of emergency, inpatient, and psychiatric health care services.[102] Participants in this study also indicated that they were better able to manage chronic physical medical conditions like diabetes, arthritis, and HIV and were able to achieve other wellness goals such as, weight loss, increased exercise, better nutrition, and smoking cessation.[103] Emergency department visits are indicators of general health status, so a reasonable correlation can be drawn between the effects of individual choice in health care and better health outcomes, in part because of the possibility of increased utilization of preventive care, and other factors. Though not easily modeled, a safe assertion can be made that PWDD with improved health status will utilize fewer, and less expensive, health care services.[104]

76. In addition to better health outcomes and decreased use of health care services, facilitated SDM (through SDMAs) may reduce health care providers' concerns as to whether a PWDD has capacity to make medical decisions, and the associated costs of resolving these concerns.[105] Without an SDMA, making a determination about capacity can involve navigating a labyrinth of laws and regulations with different coverages and requirements for obtaining substituted consent.[106] Lawyers and specialized physicians may be required to determine capacity in these situations – a time consuming and costly process for health care providers.[107] This situation can even arise during routine care provided by physicians

[102] Croft, Bevin and Parish, Susan. "Participants' Assessment of the Impact of Behavioral Health Self-Direction on Recovery." Community Mental Health Journal. October 2016.
[103] Ibid.
[104] C.f. Dept. of Health and Human Services, Centers for Medicaid & Medicaid Services , SHO# 21-001 RE: Opportunities in Medicaid and CHIP to Address Social Determinants of Health (SDOH)(Jan. 7, 2021) (encouraging health promotion to reduce Medicaid healthcare costs), and see, e.g., Peeler, Andrew W. *Strategies for Cost Saving Through Social Determinants of Health,* Journal of Healthcare Management Vol 64(4) (2019) ; Ravesloot, Craig et al., *Promotion Living Well With a Disability Health Intervention: Improved Health Status for Consumers and Lower Costs for Health Care Policymakers*, Rehabilitation Psychology 50(3), Chapman LS., Meta-evaluation of worksite health promotion economic return studies: 2005 update. *Am J Health Promot*. 2005 Jul-Aug;19(6):1-11
[105] Glen, Kristin Booth. "Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project." Albany Government Law Review. May 2020
[106] Ibid.
[107] Ibid.

and dentists if the physician or dentist does not accept the consent of the PWDD.[108] If a person's consent, or their health care proxy is not accepted, the PWDD must forego treatment (which can lead to subsequent health issues) or a guardianship proceeding must be commenced.[109] The same inefficiencies and costly use of resources can be applied to the banking industry when financial institutions do not believe a PWDD has capacity to make decisions about routine transactions like withdrawing money from a bank account, or signing a mortgage or personal loan.

77. **Increased Likelihood of Being Employed and Experiencing Workplace Inclusion.** Research shows that students who have developed self-determination skills are more likely to successfully transition to adulthood and secure employment.[110] An analysis of 779 students with developmental and learning disabilities found that self-determination and empowerment to make decisions had a positive impact on employment.[111] Employment is not only a means of generating income. Positive employment outcomes for PWDD have also been connected to increased self-confidence, self-esteem, and feelings of mastery.[112] The researchers in Bulgaria asserted that facilitated SDM increases self-confidence, self-esteem, and feelings of mastery created by employment and also widens social networks and motivates PWDD.[113] These non-financial benefits of employment improve employment opportunities overall through the creation of social identity and status, social contracts and supports, and a means of structuring and occupying time.[114] Employment can be crucial for PWDD as they are particularly sensitive to the negative impacts of unemployment and the associated loss of structure, identity, and purpose.[115] PWDD are often already socially excluded as a result of their disability, and this exclusion can be exacerbated by unemployment.[116] Social networks may become narrower or disappear, and

[108] Ibid.
[109] Ibid.
[110] Wehmeyer, Michael and Schwartz, Michelle. "Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities." Exceptional Children. 1997.
[111] Shogren, Karrie A., et al. "Relationships Between Self-Determination and Postschool Outcomes for Youth With Disabilities." The Journal of Special Education. 2015.
[112] Cook, Judith A. et al. "Mental Health Self-Directed Care Financing: Efficacy in Improving Outcomes and Controlling Costs for Adults With Serious Mental Illness. Psychiatric Services. March 2019.
[113] "Cost Benefit Analysis of Supported Decision-Making." Bulgarian Center for Not-for-Profit-Law. 2014.
[114] Ibid.
[115] Ibid.
[116] Ibid.

social functioning, motivation, and interest may be negatively impacted without employment.[117]

78. OPWDD's transition away from sheltered workshops–segregated places of employment for PWDD—began in 2013, and funding for sheltered workshops ended in 2020.[118] In 2014, there were approximately 8,100 people participating in sheltered workshops.[119] OPWDD estimated that half of people working in sheltered workshops would be able to transition to competitive employment and half would not.[120] Applying the 50% estimate to the total number of people participating in sheltered workshops (8,100), Stout estimates that 4,050 people would not transition to competitive employment. Two options for people not transitioning to competitive employment are supported employment or day habilitation.

79. Supported employment provides PWDD appropriate, ongoing supports that are necessary for successful employment in a competitive work environment.[121] Furthermore, supported employment takes place at employers within the community where PWDD are interacting with people who do not have IDD, increasing inclusiveness.[122] Qualitatively, the value of supported employment can be described as reducing the exclusion of PWDD from social places (like jobs, for example), increasing the confidence and sense of self-worth of PWDD, and developing a higher quality of life for PWDD.[123] Researchers in Bulgaria also found these qualitative elements of value when exploring the relationship between facilitated SDM and employability, and how employability reduces exclusion by increasing the confidence of PWDD and widening their social networks.[124] This research states, "these effects improve persons with disabilities' employment opportunities and could yield substantial economic benefits."[125] Because the impacts of supported employment and facilitated SDM (as it relates to employment) are similar, Stout used supported employment as a reasonable proxy to estimate the economic value of facilitated SDM related to employment. The economic value of facilitated SDM as it relates to employment

[117] Ibid.
[118] Ibid.
[119] "Open Minds: OPWDD releases plan to eliminate sheltered workshops." New York Association of Psychiatric Rehabilitation Services, Inc. November 4, 2013.
[120] Ibid.
[121] "What Parents Need to Know About Supported Employment for Individuals with Multiple Disabilities." Family Connect. N.d. and Wehman, Paul and Bricout, John. "Supported Employment: Critical Issues and New Directions." Sage Journals. 1996.
[122] Ibid.
[123] Galindo, Nellie. "Benefits of Supported Employment." Relias. October 29, 2020.
[124] "Cost Benefit Analysis of Supported Decision-Making." Bulgarian Center for Not-for-Profit-Law. 2014.
[125] Ibid.

can be estimated by comparing the cost of an inclusive work environment (i.e., supported employment) to the cost of an exclusive work / volunteer environment (i.e., day habilitation).

80. In 2020, payments made through HCBS waivers in New York for supported employment totaled approximately $72 million across 9,680 people for an approximate per person annual cost of $7,450. During the same period, payments made through HCBS waivers in New York for day habilitation totaled approximately $1.46 billion across 45,218 people for an estimated per person cost of $32,725.[126]

Estimated Net Present Value to New York of Facilitated SDM and SDMAs

81. Stout developed a methodology for estimating the economic benefits that may be recognized by New York if facilitated SDM that leads to legally recognized SDMAs were made available to PWDD. There is currently limited research and data related to the qualitative and quantitative impacts of facilitated SDM and / or SDMA legislation. Stout has used the experience and expertise of stakeholders and experts across New York to inform its analyses and complement what research was identified and could be reasonably relied on. These stakeholders included:

    - OPWDD;
    - SDMNY Project at Hunter College / City University of New York;
    - New York Civil Liberties Union;
    - AIM Services, Inc., a large provider of services to PWDD and Fiscal Intermediary for self-directing PWDD;
    - New York Housing Resource Center for People with Intellectual and Developmental Disabilities;
    - New York Alliance for Inclusion and Innovation, a leading association of provider agencies; and
    - Prisoners' Legal Services.

82. Estimating the economic benefits of facilitated SDM that New York may realize requires recognition that there are uncertainties related to participation in facilitated SDM by PWDD and a variety of individual circumstances (e.g., cognitive function, age, living arrangements, family dynamics, generalized services needs) that will impact the magnitude of cost savings accruing to New York. This is true even for the population of more than 150 diverse Decision-Makers in the SDMNY Project – each Decision-Maker's

[126] https://opwdd.ny.gov/data/services-funded-fee-service-medicaid-2020#comprehensive-hcbs-waiver-services

circumstance is unique, and consistent data collection about quantitative impacts / outcomes can be challenging and highly variable. It is also important to note that SDMNY processes and its facilitation service delivery model evolved during the course of its work and may not have always mirrored the expected service delivery model that would be implemented through SDMA legislation and subsequent OPWDD regulations. For this reason, Stout worked closely with SDMNY to understand the qualitative impact of its services and of facilitated SDM and SDMAs, but did not conduct a quantitative analysis of specific realized and projected outcomes from the 140 individual Decision-Makers served by the program.

83. A reasonable assessment of the economic benefits of facilitated SDM involves considering a range of criteria including the annual cost of varying levels of congregate care, the number of years of facilitated SDM and/or the use of legally recognized SDMAs needed before recognizing the benefit, the number of years of facilitated SDM from which individuals will benefit, the annual cost of Medicaid-provided health care and generalized services, utilization rates of Medicaid-provided health care and generalized services, inflation and reasonable discount rates that can incorporate elements of risk and uncertainty of expected future outcomes, and the one-time costs of facilitated SDM. Because of the number of uncertainties, it is more appropriate to consider how these unknown factors may be reflected in various reasonable scenarios than to assume a particular point estimate of individual or generalized outcomes.

84. Stout analyzed various scenarios and incorporated feedback from experts, disability rights advocates across New York, as well as insights from OPWDD and from those with on-the-ground experience of the SDMNY pilot project. Through this process emerged four primary scenarios in which New York will likely realize significant cost savings by promoting the use of facilitated SDM as enabled by the recently enacted SDMA legislation. These scenarios are described in greater detail in the following paragraphs and include potential cost savings related to congregate care, emergency department use, and generalized services use.

85. For each of these scenarios, Stout calculated the net present value of expected future cash flow from scenarios PWDD may experience without facilitated SDM and the net present value of expected future cash flows from scenarios PWDD may experience with facilitated SDM. The difference between these two estimations represents the net present value of the expected benefit to New York of facilitated SDM. Net present value is a financial analysis that considers an expected future stream of cash flows (in this case, the costs of congregate care, emergency department care, and generalized services) and measures the

present value of that future income stream (i.e., what the future cash flows are worth today) using a discount rate that considers the risk and uncertainty of those future cash flows.

86. When calculating net present value, the discount rate considers the time value of money and the risks and uncertainty of expected future cash flows. Time value of money is a financial concept that money today is worth more than the same amount in the future due to its earning potential. Uncertainty is inherent in any projection of future events – it is impossible to know exactly what will happen in the future. Because of the uncertainties related to the potential economic benefits of facilitated SDM, the discount rate is an important input in Stout's scenario analyses.

87. In the context of the uncertainty associated with cash flow arising from individual human behavior, as is the case in the scenario analyses described herein, one can draw on the methods of determining discount rates commonly used and accepted by the courts involving personal economic damages – that is, matters in which a person's future education, employment, medical needs and other costs or opportunities may have been harmed. In such matters it is well-established that a discount rate would be applied to future cash flow in order to estimate a present value.

88. The discount rate that is often used in such cases is the rate of return for a reasonably safe investment such that if the present value was invested today it would be able to pay the future costs. In some instances, courts will adopt a "total offset" methodology – where the expected growth rate of earnings is offset by the discount rate – such that no net discount rate is applied (or that the discount rate and earnings growth rate are equivalent and offset each other).

89. The rate of return on safe investments is often estimated using current rates of return for high grade U.S. Treasury of bond investments. The October 1, 2021 interest rate release of the Board of Governors of the Federal Reserve System[127] indicates that the yield on 20-year U.S. Treasuries is approximately 2.0%. The economic date published by the St. Louis Federal Reserve indicates that the yield on 10-year high-quality corporate bonds is approximately 2.35%[128] and AAA bonds are approximately 2.70%[129].

90. For purposes of Stout's scenario analyses herein, we have considered discount rates ranging from 0% (a total offset approach, as described above) to 5% (which would consider

[127] https://www.federalreserve.gov/releases/h15/
[128] https://fred.stlouisfed.org/series/HQMCB10YR
[129] https://fred.stlouisfed.org/series/DAAA

additional risk or uncertainty associated with the successful implementation of facilitated SDM).

91. Net present value calculations also consider the cost of providing the services. A positive net present value indicates that the present value of the monetary benefit of a project or initiative is greater than the cost. A negative net present value indicates that the present value of the cost of a project or initiative is greater than the monetary benefits. Stout's net present value scenario analyses of facilitated SDM incorporated a mid-year convention to appropriately consider that costs and benefits would accrue on a pro-rata basis in each year of the scenario forecast. Each of Stout's scenario analyses uses a 20-year forecast period, though the period of recognized costs or benefits are less than this in certain scenarios.

Other Analysis Considerations

92. The range of scenarios and circumstances experienced by PWDD who may use facilitated SDM / legally recognized SDMAs is infinite, and it is impossible to model every scenario. Understanding this, there are important considerations when interpreting the results of Stout's scenario analyses, all of which Stout considered in its analyses (each described further throughout this section): (1) the overall aging of the PWDD population in New York, in combination with higher birth rates of PWDD; (2) a reasonable distribution of scenario outcomes; and (3) The limited initial capacity of the proposed FTREC of 500 PWDD per year.

93. **Aging of PWDD and Higher Birth Rates of PWDD.** Stout understands that a significant portion of PWDD currently living in New York with their parents or guardians will likely need to enter congregate care either as their parents or guardians age and become unable to care for them or when their parents or guardians pass away. Stout also understands that greater numbers of people are being born with developmental disabilities.[130] The higher birth rate will eventually increase the need for congregate care and other services used by PWDD. If congregate care budgets / funding are reduced and capacity in these facilities is limited, it is possible that without facilitated SDM, increasing numbers of PWDD will experience homelessness or others will be experience homelessness resulting from the reduction of available congregate care capacity. The cost of homelessness has been

[130] "Increase in Developmental Disabilities Among Children in the United States." Centers for Disease Control and Prevention. Citing Zablotsky, Benjamin et al. "Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009-2017." Journal of the American Academy of Pediatrics. 2019.

researched extensively in New York, and the social safety net responses to homelessness are incredibly expensive[131] – especially compared to the cost of facilitated SDM.

94. **A Reasonable Distribution of Scenario Outcomes.** Stout's analyses contemplated a reasonable distribution of scenarios. As Stout constructed its scenarios, it considered that research has shown that facilitated SDM is likely to reduce the number of guardianships in New York, delay or avoid entry to congregate care, decrease overall use of HCBS waiver services, and may decrease use of emergency department care and generalized services. However, Stout also recognized that not all (but certainly the majority) of PWDD using facilitated SDM would result in a positive net present value for New York. There will be scenarios where facilitated SDM does not reduce costs or result in a positive net present value for New York. These will be scenarios where the projected one-time per person cost of facilitated SDM of $7,000– is more than the costs saved, including those scenarios where a PWDD takes advantage of available facilitation services, but does not ultimately execute or use an SDMA to any measurable economic advantage.

95. For example, a person may use facilitation services, and subsequently fail to execute an SDMA, or alternatively may execute an SDMA but never reduce their use of HCBS waiver services, realize supported employment, or decrease their use of health care services. In this scenario, there would be a negative net present value to New York of $7,000, assuming this person would never have been subject to a guardianship, and the costs associated those proceedings. That is, facilitated SDM would cost marginally more ($7,000) than the cost savings realized by New York as a result of facilitated SDM. However, stakeholders in New York have described this scenario as very unlikely and unexpected in any material number. Stout does recognize that while these scenarios may be unlikely and unexpected, they are still possible and important to consider. More importantly though, is that over a portfolio of scenarios, New York would recognize a significant positive net present value if facilitation services were available and decisions made in accordance with SDMAs were legally recognized. The positive net present value, even in the presence of unique individual scenarios with negative net present values, is because in a reasonable distribution of scenario outcomes, the net cost savings will be significantly greater than the required investment. For example, there will be PWDD using facilitated SDM who will have positive net present values of thousands to hundreds of thousands of dollars. These significant positive net present values would more than offset the few scenarios with small negative net present values. Furthermore, in scenarios where a Decision-Maker uses

[131] Routhier, Giselle. "State of the Homeless 2021." Coalition for the Homeless. 2021. See also "State of the Homeless" reports for 2019 and 2020.

facilitated SDM for years but does not recognize the specific benefits quantified in Stout's analyses, other unquantifiable benefits are likely being realized, such as Decision-Maker having autonomy over their life and the contribution of SDM towards reducing prejudice against PWDD.

96. **Initial Limited Capacity of FTREC.** Stout understands that there is an expected one-time cost of $7,000 per person using facilitated SDM in New York. These costs are associated with a Facilitation Training, Resource and Education Center (FTREC). The FTREC would be responsible for training facilitators, developing materials for facilitators to use in their work with Decision-Makers and their supporters, and providing mentors for all facilitators. The one-time per person cost of $7,000 equates to an annual cost of approximately $3.5 million for 500 Decision-Makers each year. Stout has included the cost of facilitated SDM and the FTREC's operations in its calculations to be conservative. As previously discussed, even when including the cost of facilitated SDM, New York would expect a positive net value across a portfolio of reasonable scenarios.

Scenario 1: Achieving an Exit from Congregate Care through Facilitated SDM

97. Stout analyzed scenarios where facilitated SDM may result in someone currently living in congregate care exiting congregate care and reducing use of emergency department care and generalized services. Table 1 is an illustration of inputs to scenarios used to calculate the net present value of facilitated SDM when the Decision-Maker may be able to move out of congregate care through the use of facilitated SDM and SDMAs. In this scenario, a Decision-Maker is living in congregate care for 4 years before receiving the benefit of facilitated SDM (row 2 in Table 1). Because of facilitated SDM, in this scenario, the Decision-Maker is able to exit congregate care for 13 years (row 3 in Table 1) and re-enters congregate care after year 17 (row 4 in Table 1). Because of facilitated SDM, the Decision-Maker utilizes emergency department care twice per year (row 7 in Table 1) compared to 5 times per year without facilitated SDM (row 6 in Table 1). The benefit of facilitated SDM starts after 3 years (row 8 in Table 1) and continues for 15 years (row 9 in Table 1) in this scenario. Furthermore, the Decision-Maker decreases the use of generalized services. This benefit of facilitated SDM starts after 5 years (row 14 in Table 1) and continues for 15 years (row 15 in Table 1). Stout understands from SDMNY that there is an estimated one-time cost of $7,000 per person using facilitated SDM (row 19 in Table 1) and an estimated annual administrative cost of $600 per person using facilitated SDM (row 20 in Table 1).

	Congregate Care	
1	Estimated annual cost to NYS of congregate care [a]	$ 65,000
2	Years FSDM / SDMA before benefit	4
3	Years of FSDM / SDMA benefit	13
4	Last year of congregate care benefit	17
	Emergency Department	
5	Estimated Medicaid cost per visit to emergency department [b]	$ 420
6	Current annual emergency department visits per person	5
7	Estimated annual emergency department visits with FSDM and SDMA legislation	2
8	Years of FSDM / SDMA before emergency department benefit	3
9	Years of emergency department benefit	15
10	Last year of emergency department benefit	18
	Generalized Services	
11	Estimated annual cost of generalized services per person [c]	$ 32,000
12	Portion paid by NYS	50.0%
13	Estimated annual decrease in use of generalized services because of FSDM	5.0%
14	Years of FSDM / SDMA before generalized services benefit	5
15	Years of generalized services benefit	15
16	Last year of generalized services benefit	20
	Other	
17	Estimated annual inflation [d]	3.5%
18	Discount rate	5.0%
19	Estimated one-time per person facilitated SDM cost to NYS	$ 7,000
20	Estimated annual per person facilitated SDM administrative cost to NYS	$ 600

[a] Estimated using Medicaid fee-for-service payments by OPWDD for residential habilitation.
[b] "Trends in Utilization of Emergency Department Services, 2009-2018." U.S. Department of Health and Human Services Office of the Assistance Secretary for Planning and Evaluation. March 2021.
[c] Estimated by Stout using data from OPWDD indicating that approximately $1.4 billion was spent to provide day habilitation services to approximately 45,000 people in 2019.
[d] Genworth's 2017 Cost of Care Survey found that nursing home care had a five-year annual growth rate of between 3.3% (semi-private room) and 3.8% (private room).

Table 1

98. With facilitated SDM, Stout estimated that for a person in the scenario described in the previous paragraph, the cost of congregate care, emergency department care, and generalized services over a 20-year period has a net present value to New York of approximately $436,800. Without facilitated SDM, Stout estimated a net present value of approximately $921,000. The difference between these two net present values – $484,200 – is the estimated net present value to New York of facilitated SDM for someone in this scenario. Table 2 shows this scenario with facilitated SDM, and Table 3 shows this scenario without facilitated SDM. The estimated net present values using discount rates from 0% to 4% are:

- 0% - net present value of $1,253,700
- 1% - net present value of $1,032,600
- 2% - net present value of $852,100
- 3% - net present value of $704,500

- 4% - net present value of $583,500

With FSDM and SDMA Legislation						
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Estimated Annual Cost of FSDM	Cumulative Cost of Congregate Care, Emergency Department Care, Generalized Services, and FSDM	Present Value of Congregate Care, Emergency Department Care, Generalized Services, and FSDM
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 7,600	$ 90,700	$ 86,400
Year 2	67,300	2,200	16,600	700	177,500	165,000
Year 3	69,700	2,300	17,200	700	267,400	236,700
Year 4	72,200	1,000	17,900	700	359,200	302,900
Year 5	0	1,000	18,600	700	379,500	304,700
Year 6	0	1,000	18,100	800	399,400	305,400
Year 7	0	1,100	18,700	800	420,000	305,900
Year 8	0	1,100	19,400	800	441,300	306,100
Year 9	0	1,200	20,100	800	463,400	306,100
Year 10	0	1,200	20,800	900	486,300	306,000
Year 11	0	1,200	21,500	900	509,900	305,500
Year 12	0	1,300	22,200	900	534,300	304,900
Year 13	0	1,300	23,000	1,000	559,600	304,100
Year 14	0	1,400	23,800	1,000	585,800	303,200
Year 15	0	1,400	24,700	1,000	612,900	302,100
Year 16	0	1,500	25,500	0	639,900	300,400
Year 17	0	1,500	26,400	0	667,800	298,600
Year 18	118,000	1,600	27,300	0	814,700	346,900
Year 19	122,200	4,900	28,300	0	970,100	393,400
Year 20	126,500	5,100	29,300	0	1,131,000	436,800

Table 2

Without FSDM and SDMA Legislation					
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Cumulative Cost of Congregate Care, Emergency Department Care, and Generalized Services	Present Value of Congregate Care, Emergency Department Care, and Generalized Services
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 83,100	$ 79,200
Year 2	67,300	2,200	16,600	169,200	157,300
Year 3	69,700	2,300	17,200	258,400	228,800
Year 4	72,200	2,400	17,900	350,900	295,900
Year 5	74,800	2,500	18,600	446,800	358,800
Year 6	77,500	2,600	19,300	546,200	417,700
Year 7	80,300	2,700	20,000	649,200	472,800
Year 8	83,200	2,800	20,700	755,900	524,300
Year 9	86,200	2,900	21,500	866,500	572,400
Year 10	89,300	3,100	22,300	981,200	617,300
Year 11	92,500	3,300	23,100	1,100,100	659,100
Year 12	95,800	3,500	24,000	1,223,400	698,100
Year 13	99,200	3,700	24,900	1,351,200	734,300
Year 14	102,700	3,900	25,800	1,483,600	767,900
Year 15	106,300	4,100	26,800	1,620,800	798,900
Year 16	110,100	4,300	27,800	1,763,000	827,600
Year 17	114,000	4,500	28,800	1,910,300	854,100
Year 18	118,000	4,700	29,900	2,062,900	878,400
Year 19	122,200	4,900	31,000	2,221,000	900,700
Year 20	126,500	5,100	32,100	2,384,700	921,000

Table 3

99. The magnitude of net present value to New York will vary based on the number of years before the benefit of facilitated SDM and the number of years of benefit of facilitated SDM in all cost categories – congregate care, emergency department care, and generalized services. Table 4 is a sensitivity table showing various scenarios based on a variety of years before benefit and of benefit. Sensitivity tables are common analytical tools used to see how a dependent variable changes when certain assumptions / inputs are changed. For example, in Table 4, the dependent variable (the orange cell) is the estimated net present value of facilitated SDM, which is based on the years before benefit and of benefit used in Table 1. If the years before benefit was changed to 7 and the years of benefit was changed to 13, the net present value would be $536,000. The blank cells in the lower right portion of the table indicate scenarios not possible in Stout's 20-year model. For example, in a 20-year model, it is not possible to have 16 years before benefit and 7 years of benefit because the total years is more than 20. It is important to note that every scenario in Table 4 results in a positive net present value. Table 5 shows how the net present value changes based on the years of benefit and the annual cost of congregate care.

		Years before benefit					
	$ 484,200	**1**	**4**	**7**	**10**	**13**	**16**
Years of benefit	**1**	42,100	45,000	48,300	51,900	55,800	60,200
	4	125,800	138,100	151,800	166,800	183,400	201,800
	7	218,900	241,600	266,700	294,400	325,000	
	10	322,400	356,600	394,300	436,000		
	13	437,400	484,200	536,000			
	16	564,500	625,400				

Table 4

		Years of benefit					
	$ 484,200	**1**	**4**	**7**	**10**	**13**	**16**
Annual cost of congregate care	**$ 30,000**	29,500	72,600	120,600	174,100	233,500	299,100
	35,000	31,700	82,100	138,000	200,200	269,400	345,800
	40,000	33,900	91,300	155,100	225,900	304,600	391,600
	45,000	36,200	100,700	172,300	251,900	340,400	438,100
	50,000	38,400	110,100	189,700	278,100	376,300	484,800

Table 5

Scenario 2: Delaying Entry into Congregate Care through Facilitated SDM

100. The second set of scenarios that Stout analyzed considered the population of PWDD currently living with their parents. As parents age, caring for their adult children with development disabilities can become increasingly challenging and often results in

congregate care entry for the adult children. Another example of a PWDD who is considered in this is a person who is under the age of 18 and is living in residential schools (inside and outside of New York) and will be moving home with their parents when they reach age 18. Stout understands that while congregate care entry may be inevitable, delaying entry – even by a few years – through facilitated SDM will likely result in cost savings to New York. The inputs in Table 6 were used to calculate the net present value of facilitated SDM for a scenario where congregate care entry was delayed and emergency department care and generalized services use decreased.

	Congregate Care	
1	Estimated annual cost to NYS of congregate care [a]	$ 65,000
2	Years FSDM / SDMA before benefit	0
3	Years of FSDM / SDMA benefit	7
4	Last year of congregate care benefit	7
	Emergency Department	
5	Estimated Medicaid cost per visit to emergency department [b]	$ 420
6	Current annual emergency department visits per person	5
7	Estimated annual emergency department visits with FSDM and SDMA legislation	2
8	Years of FSDM / SDMA before emergency department benefit	2
9	Years of emergency department benefit	5
10	Last year of emergency department benefit	7
	Generalized Services	
11	Estimated annual cost of generalized services per person [c]	$ 32,000
12	Portion paid by NYS	50.0%
13	Estimated annual decrease in use of generalized services because of FSDM	5.0%
14	Years of FSDM / SDMA before generalized services benefit	1
15	Years of generalized services benefit	12
16	Last year of generalized services benefit	13
	Other	
17	Estimated annual inflation [d]	3.5%
18	Discount rate	5.0%
19	Estimated one-time per person facilitated SDM cost to NYS	$ 7,000
20	Estimated annual per person facilitated SDM administrative cost to NYS	$ 600

[a] Estimated using Medicaid fee-for-service payments by OPWDD for residential habilitation.
[b] "Trends in Utilization of Emergency Department Services, 2009-2018." U.S. Department of Health and Human Services Office of the Assistance Secretary for Planning and Evaluation. March 2021.
[c] Estimated by Stout using data from OPWDD indicating that approximately $1.4 billion was spent to provide day habilitation services to approximately 45,000 people in 2019.
[d] Genworth's 2017 Cost of Care Survey found that nursing home care had a five-year annual growth rate of between 3.3% (semi-private room) and 3.8% (private room).

Table 6

101. In this scenario, a person who is currently living with their aging parents is able to delay entry into congregate care for 7 years (row 3 in Table 6) because of facilitated SDM. Because of facilitated SDM, they utilize emergency department care twice per year (row 7 in Table 6) compared to 5 times per year without facilitated SDM (row 6 in Table 6). This benefit of facilitated SDM starts after 2 years (row 8 in Table 6) and continues for 5 years

(row 9 in Table 6). Furthermore, they decrease their use of generalized services. This benefit of facilitated SDM starts after 1 year (row 14 in Table 6) and continues for 12 years (row 15 in Table 6).

102. With facilitated SDM, Stout estimated that for a person in the scenario described in the previous paragraph the cost of congregate care, emergency department care, and generalized services over a 20-year period have a net present value to New York of approximately $722,600, which includes the cost of facilitated SDM. Without facilitated SDM, Stout estimated a net present value of approximately $921,000. The difference between these two net present values – $198,400 – is the estimated net present value to New York of facilitated SDM for someone in this scenario. Table 7 shows this scenario with facilitated SDM, and Table 8 shows this scenario without facilitated SDM. The estimated net present values using discount rates from 0% to 4% are:

    - 0% - net present value of $513,800
    - 1% - net present value of $423,200
    - 2% - net present value of $349,300
    - 3% - net present value of $288,800
    - 4% - net present value of $239,100

With FSDM and SDMA Legislation						
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Estimated Annual Cost of FSDM	Cumulative Cost of Congregate Care, Emergency Department Care, Generalized Services, and FSDM	Present Value of Congregate Care, Emergency Department Care, Generalized Services, and FSDM
Year 1	$ 0	$ 2,100	$ 16,000	$ 7,600	$ 25,700	$ 24,500
Year 2	0	2,200	15,800	700	44,400	41,300
Year 3	0	900	16,300	700	62,300	55,200
Year 4	0	1,000	16,900	700	80,900	68,300
Year 5	0	1,000	17,500	700	100,100	80,400
Year 6	0	1,000	18,100	800	120,000	91,800
Year 7	0	1,100	18,700	800	140,600	102,400
Year 8	83,200	2,800	19,400	800	246,800	171,200
Year 9	86,200	2,900	20,100	800	356,800	235,700
Year 10	89,300	3,100	20,800	900	470,900	296,300
Year 11	92,500	3,300	21,500	900	589,100	353,000
Year 12	95,800	3,500	22,200	900	711,500	406,000
Year 13	99,200	3,700	23,000	0	837,400	455,100
Year 14	102,700	3,900	25,800	0	969,800	502,000
Year 15	106,300	4,100	26,800	0	1,107,000	545,700
Year 16	110,100	4,300	27,800	0	1,249,200	586,500
Year 17	114,000	4,500	28,800	0	1,396,500	624,400
Year 18	118,000	4,700	29,900	0	1,549,100	659,600
Year 19	122,200	4,900	31,000	0	1,707,200	692,300
Year 20	126,500	5,100	32,100	0	1,870,900	722,600

Table 7

Without FSDM and SDMA Legislation					
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Cumulative Cost of Congregate Care, Emergency Department Care, and Generalized Services	Present Value of Congregate Care, Emergency Department Care, and Generalized Services
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 83,100	$ 79,200
Year 2	67,300	2,200	16,600	169,200	157,300
Year 3	69,700	2,300	17,200	258,400	228,800
Year 4	72,200	2,400	17,900	350,900	295,900
Year 5	74,800	2,500	18,600	446,800	358,800
Year 6	77,500	2,600	19,300	546,200	417,700
Year 7	80,300	2,700	20,000	649,200	472,800
Year 8	83,200	2,800	20,700	755,900	524,300
Year 9	86,200	2,900	21,500	866,500	572,400
Year 10	89,300	3,100	22,300	981,200	617,300
Year 11	92,500	3,300	23,100	1,100,100	659,100
Year 12	95,800	3,500	24,000	1,223,400	698,100
Year 13	99,200	3,700	24,900	1,351,200	734,300
Year 14	102,700	3,900	25,800	1,483,600	767,900
Year 15	106,300	4,100	26,800	1,620,800	798,900
Year 16	110,100	4,300	27,800	1,763,000	827,600
Year 17	114,000	4,500	28,800	1,910,300	854,100
Year 18	118,000	4,700	29,900	2,062,900	878,400
Year 19	122,200	4,900	31,000	2,221,000	900,700
Year 20	126,500	5,100	32,100	2,384,700	921,000

Table 8

103. As with the first scenario, the magnitude of net present value to New York will vary based on the number of years before the benefit of facilitated SDM and the number of years of benefit of facilitated SDM in all cost categories – congregate care, emergency department care, and generalized services. Table 9 is a sensitivity table for this scenario showing how the net present value changes based on the number of years before benefit and of benefit. Table 10 shows how the net present value changes based on the number of years before benefit and the discount rate. It is important to note that every scenario in Tables 9 and 10 result in a positive net present value.

		Years before benefit					
	$ 198,400	**1**	**4**	**7**	**10**	**13**	**16**
Years of benefit	**1**	28,700	31,600	34,800	38,400	42,400	46,700
	4	112,400	124,700	138,300	153,400	170,000	188,300
	7	205,400	228,200	253,300	281,000	311,600	
	10	308,900	343,100	380,900	422,600		
	13	423,500	470,300	522,100			
	16	549,900	610,800				

Table 9

		Years before benefit					
	$ 198,400	**1**	**4**	**7**	**10**	**13**	**16**
Discount rate	**5%**	205,400	228,200	253,300	281,000	311,600	188,300
	10%	82,900	92,100	102,200	113,400	125,800	76,000
	15%	34,900	38,700	43,000	47,700	52,900	32,000
	20%	15,200	16,900	18,800	20,800	23,100	13,900
	25%	6,900	7,600	8,500	9,400	10,400	6,300

Table 10

Scenario 3: Decreased Use of Emergency Department Care and Generalized Services Only through Facilitated SDM

104. The third set of scenarios that Stout analyzed considered the population of PWDD who would not exit congregate care or delay congregate care entry (i.e., would not have a change in living situation) but who would decrease their use of emergency department care and generalized services because of facilitated SDM. Stout understands that while someone using facilitated SDM may still need to reside in a congregate care setting, there is still value of facilitated SDM in these circumstances. The inputs in Table 11 were used to calculate the net present value of facilitated SDM for a scenario where someone remains in congregate care, but facilitated SDM has resulted in decreased use of emergency department care and generalized services.

	Congregate Care	
1	Estimated annual cost to NYS of congregate care [a]	$ 65,000
2	Years FSDM / SDMA before benefit	0
3	Years of FSDM / SDMA benefit	0
4	Last year of congregate care benefit	0
	Emergency Department	
5	Estimated Medicaid cost per visit to emergency department [b]	$ 420
6	Current annual emergency department visits per person	5
7	Estimated annual emergency department visits with FSDM and SDMA legislation	2
8	Years of FSDM / SDMA before emergency department benefit	2
9	Years of emergency department benefit	16
10	Last year of emergency department benefit	18
	Generalized Services	
11	Estimated annual cost of generalized services per person [c]	$ 32,000
12	Portion paid by NYS	50.0%
13	Estimated annual decrease in use of generalized services because of FSDM	5.0%
14	Years of FSDM / SDMA before generalized services benefit	2
15	Years of generalized services benefit	18
16	Last year of generalized services benefit	20
	Other	
17	Estimated annual inflation [d]	3.5%
18	Discount rate	5.0%
19	Estimated one-time per person facilitated SDM cost to NYS	$ 7,000
20	Estimated annual per person facilitated SDM administrative cost to NYS	$ 600

[a] Estimated using Medicaid fee-for-service payments by OPWDD for residential habilitation.
[b] "Trends in Utilization of Emergency Department Services, 2009-2018." U.S. Department of Health and Human Services Office of the Assistance Secretary for Planning and Evaluation. March 2021.
[c] Estimated by Stout using data from OPWDD indicating that approximately $1.4 billion was spent to provide day habilitation services to approximately 45,000 people in 2019.
[d] Genworth's 2017 Cost of Care Survey found that nursing home care had a five-year annual growth rate of between 3.3% (semi-private room) and 3.8% (private room).

Table 11

105. In this scenario, a person remains in a congregate care setting or enters congregate care as planned and therefore has 0 years of facilitated SDM benefit associated with congregate care (row 3 in Table 11). However, because of facilitated SDM, they utilize emergency department care twice per year (row 7 in Table 11) compared to 5 times per year without facilitated SDM (row 6 in Table 11). This benefit of facilitated SDM starts after 2 years (row 8 in Table 11) and continues for 16 years (row 9 in Table 11). Furthermore, they decrease their use of generalized services. This benefit of facilitated SDM starts after 2 years (row 14 in Table 11) and continues for 18 years (row 15 in Table 11).

106. With facilitated SDM, Stout estimated that for a person in the scenario described in the previous paragraph the cost of emergency department care and generalized services over a 20-year period have a net present value to New York of approximately $904,400, which includes the cost of facilitated SDM. Without facilitated SDM, Stout estimated a net present value of approximately $921,000. The difference between these two net present values – $16,600 – is the estimated net present value to New York of facilitated SDM for someone in this scenario. Table 12 shows this scenario with facilitated SDM, and Table 13 shows this scenario without facilitated SDM. The estimated net present values using discount rates from 0% to 4% are:

    - 0% - net present value of $42,900
    - 1% - net present value of $35,400
    - 2% - net present value of $29,200
    - 3% - net present value of $24,100
    - 4% - net present value of $19,900

With FSDM and SDMA Legislation						
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Estimated Annual Cost of FSDM	Cumulative Cost of Congregate Care, Emergency Department Care, Generalized Services, and FSDM	Present Value of Congregate Care, Emergency Department Care, Generalized Services, and FSDM
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 7,600	$ 90,700	$ 86,400
Year 2	67,300	2,200	16,600	700	177,500	165,000
Year 3	69,700	900	16,300	700	265,100	234,700
Year 4	72,200	1,000	16,900	700	355,900	300,100
Year 5	74,800	1,000	17,500	700	449,900	361,300
Year 6	77,500	1,000	18,100	800	547,300	418,500
Year 7	80,300	1,100	18,700	800	648,200	472,100
Year 8	83,200	1,100	19,400	800	752,700	522,100
Year 9	86,200	1,200	20,100	800	861,000	568,800
Year 10	89,300	1,200	20,800	900	973,200	612,300
Year 11	92,500	1,200	21,500	900	1,089,300	652,700
Year 12	95,800	1,300	22,200	900	1,209,500	690,200
Year 13	99,200	1,300	23,000	1,000	1,334,000	725,000
Year 14	102,700	1,400	23,800	1,000	1,462,900	757,200
Year 15	106,300	1,400	24,700	1,000	1,596,300	786,900
Year 16	110,100	1,500	25,500	1,100	1,734,500	814,300
Year 17	114,000	1,500	26,400	1,100	1,877,500	839,400
Year 18	118,000	1,600	27,300	1,100	2,025,500	862,500
Year 19	122,200	4,900	28,300	0	2,180,900	884,400
Year 20	126,500	5,100	29,300	0	2,341,800	904,400

Table 12

Without FSDM and SDMA Legislation					
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Cumulative Cost of Congregate Care, Emergency Department Care, and Generalized Services	Present Value of Congregate Care, Emergency Department Care, and Generalized Services
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 83,100	$ 79,200
Year 2	67,300	2,200	16,600	169,200	157,300
Year 3	69,700	2,300	17,200	258,400	228,800
Year 4	72,200	2,400	17,900	350,900	295,900
Year 5	74,800	2,500	18,600	446,800	358,800
Year 6	77,500	2,600	19,300	546,200	417,700
Year 7	80,300	2,700	20,000	649,200	472,800
Year 8	83,200	2,800	20,700	755,900	524,300
Year 9	86,200	2,900	21,500	866,500	572,400
Year 10	89,300	3,100	22,300	981,200	617,300
Year 11	92,500	3,300	23,100	1,100,100	659,100
Year 12	95,800	3,500	24,000	1,223,400	698,100
Year 13	99,200	3,700	24,900	1,351,200	734,300
Year 14	102,700	3,900	25,800	1,483,600	767,900
Year 15	106,300	4,100	26,800	1,620,800	798,900
Year 16	110,100	4,300	27,800	1,763,000	827,600
Year 17	114,000	4,500	28,800	1,910,300	854,100
Year 18	118,000	4,700	29,900	2,062,900	878,400
Year 19	122,200	4,900	31,000	2,221,000	900,700
Year 20	126,500	5,100	32,100	2,384,700	921,000

Table 13

107. Consistent with the previous two scenarios, the magnitude of net present value to New York will vary based on the number of years of benefit before the benefit of facilitated SDM and the number of years of benefit of facilitated SDM in emergency department care and generalized services. Table 14 is a sensitivity table for this scenario showing how the net present value changes based on the number of years before benefit and of benefit.

		Years before benefit					
	$ 16,600	**1**	**4**	**7**	**10**	**13**	**16**
Years of benefit	**1**	42,500	45,400	48,700	52,300	56,200	60,600
	4	126,200	138,500	152,200	167,200	183,800	202,200
	7	219,300	242,000	267,200	294,800	325,400	
	10	322,800	357,000	394,800	436,500		
	13	437,800	484,600	536,400			
	16	565,400	626,200				

Table 14

Scenario 4: Decreased Use of Intensive Congregate Care through Facilitated SDM

108. The fourth set of scenarios that Stout analyzed considered PWDD who would not exit congregate care but would likely move to a less intensive congregate care setting because of facilitated SDM (e.g., from enhanced residential care to certified family care). The inputs in Table 15 were used to calculate the net present value of facilitated SDM for a scenario where someone remains in congregate care but facilitated SDM has resulted in the use of less intensive (and less expensive) congregate care.

	Congregate Care	
1	Estimated annual cost to NYS of congregate care [a]	$ 65,000
2	Estimated annual cost to NYS of congregate care (less intensive) [b]	$ 20,000
3	Years FSDM / SDMA before benefit	5
4	Years of FSDM / SDMA benefit	15
5	Last year of congregate care benefit	20
	Emergency Department	
6	Estimated Medicaid cost per visit to emergency department [c]	$ 420
7	Current annual emergency department visits per person	5
8	Estimated annual emergency department visits with FSDM and SDMA legislation	2
9	Years of FSDM / SDMA before emergency department benefit	2
10	Years of emergency department benefit	16
11	Last year of emergency department benefit	18
	Generalized Services	
12	Estimated annual cost of generalized services per person [d]	$ 32,000
13	Portion paid by NYS	50.0%
14	Estimated annual decrease in use of generalized services because of FSDM	5.0%
15	Years of FSDM / SDMA before generalized services benefit	2
16	Years of generalized services benefit	18
17	Last year of generalized services benefit	20
	Other	
18	Estimated annual inflation [e]	3.5%
19	Discount rate	5.0%
20	Estimated one-time per person facilitated SDM cost to NYS	$ 7,000
21	Estimated annual per person facilitated SDM administrative cost to NYS	$ 600

[a] Estimated using Medicaid fee-for-service payments by OPWDD for residential habilitation.
[b] Estimated using Medicaid fee-for-service payments by OPWDD for supportive residential habilitation
[c] "Trends in Utilization of Emergency Department Services, 2009-2018." U.S. Department of Health and Human Services Office of the Assistance Secretary for Planning and Evaluation. March 2021.
[d] Estimated by Stout using data from OPWDD indicating that approximately $1.4 billion was spent to provide day habilitation services to approximately 45,000 people in 2019.
[e] Genworth's 2017 Cost of Care Survey found that nursing home care had a five-year annual growth rate of between 3.3% (semi-private room) and 3.8% (private room).

Table 15

109. In this scenario, a person is living in congregate care and remains in congregate care. However, because of facilitated SDM, they are able to move to a less intenstive (and less expensive) congregate care setting. Their current congregate care living environment costs New York an estimated $65,000 per year (row 1 in Table 15). Through faciliated SDM, they move to a less intensive congregate care setting after 5 years (row 3 in Table 15), which costs New York an estimated $20,000 per year (row 2 in Table 15). The person is living in the more intenstive congregate care setting for 5 years (row 3 in Table 15) before moving to the less intenstive congregate care setting because of faciliated SDM. This scenario also considers a reduction in the use of emergency department care and generalized services consistent with Scenario 3.

110. With facilitated SDM, Stout estimated that for a person in the scenario described in the previous paragraph the cost of congregate care, emergency department care, and generalized services over a 20-year period has a net present value to New York of approximately $500,900, which includes the cost of facilitated SDM. Without facilitated SDM, Stout estimated a net present value of approximately $921,000. The difference between these two net present values – $420,100 – is the estimated net present value to New York of facilitated SDM for someone in this scenario. Table 16 shows this scenario with facilitated SDM, Table 17 shows this scenario without facilitated SDM, and Table 18 is a sensitivity table for this scenario showing how the net present value changes based on the number of years of benefit and the annual cost of congregate care. Table 19 shows how the net present value changes based on the number of years before benefit and the discount rate. It is important to note that every scenario in Tables 18 and 19 results in a positive net present value. The estimated net present values using discount rates from 0% to 4% are:

- 0% - net present value of $1,087,700
- 1% - net present value of $895,900
- 2% - net present value of $739,300
- 3% - net present value of $611,200
- 4% - net present value of $506,200

With FSDM and SDMA Legislation						
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Estimated Annual Cost of FSDM	Cumulative Cost of Congregate Care, Emergency Department Care, Generalized Services, and FSDM	Present Value of Congregate Care, Emergency Department Care, Generalized Services, and FSDM
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 7,600	$ 90,700	$ 86,400
Year 2	67,300	2,200	16,600	700	177,500	165,000
Year 3	69,700	900	16,300	700	265,100	234,700
Year 4	72,200	1,000	16,900	700	355,900	300,100
Year 5	74,800	1,000	17,500	700	449,900	361,300
Year 6	23,754	1,000	18,100	800	493,600	377,500
Year 7	24,585	1,100	18,700	800	538,800	392,400
Year 8	25,446	1,100	19,400	800	585,600	406,200
Year 9	26,336	1,200	20,100	800	634,100	418,900
Year 10	27,258	1,200	20,800	900	684,300	430,500
Year 11	28,212	1,200	21,500	900	736,200	441,100
Year 12	29,199	1,300	22,200	900	789,800	450,700
Year 13	30,221	1,300	23,000	1,000	845,400	459,500
Year 14	31,279	1,400	23,800	1,000	902,900	467,300
Year 15	32,374	1,400	24,700	1,000	962,400	474,400
Year 16	33,507	1,500	25,500	1,100	1,024,100	480,800
Year 17	34,680	1,500	26,400	1,100	1,087,800	486,400
Year 18	35,894	1,600	27,300	1,100	1,153,700	491,300
Year 19	37,150	4,900	28,300	0	1,224,100	496,400
Year 20	38,450	5,100	29,300	0	1,297,000	500,900

Table 16

Without FSDM and SDMA Legislation					
Year Entering Congregate Care	Annual Cost of Congregate Care	Annual Medicaid Cost of Emergency Department Care	Annual Cost of Generalized Services	Cumulative Cost of Congregate Care, Emergency Department Care, and Generalized Services	Present Value of Congregate Care, Emergency Department Care, and Generalized Services
Year 1	$ 65,000	$ 2,100	$ 16,000	$ 83,100	$ 79,200
Year 2	67,300	2,200	16,600	169,200	157,300
Year 3	69,700	2,300	17,200	258,400	228,800
Year 4	72,200	2,400	17,900	350,900	295,900
Year 5	74,800	2,500	18,600	446,800	358,800
Year 6	77,500	2,600	19,300	546,200	417,700
Year 7	80,300	2,700	20,000	649,200	472,800
Year 8	83,200	2,800	20,700	755,900	524,300
Year 9	86,200	2,900	21,500	866,500	572,400
Year 10	89,300	3,100	22,300	981,200	617,300
Year 11	92,500	3,300	23,100	1,100,100	659,100
Year 12	95,800	3,500	24,000	1,223,400	698,100
Year 13	99,200	3,700	24,900	1,351,200	734,300
Year 14	102,700	3,900	25,800	1,483,600	767,900
Year 15	106,300	4,100	26,800	1,620,800	798,900
Year 16	110,100	4,300	27,800	1,763,000	827,600
Year 17	114,000	4,500	28,800	1,910,300	854,100
Year 18	118,000	4,700	29,900	2,062,900	878,400
Year 19	122,200	4,900	31,000	2,221,000	900,700
Year 20	126,500	5,100	32,100	2,384,700	921,000

Table 17

		Years of benefit					
	$ 420,100	1	4	7	10	13	16
Annual cost of congregate care	$ 30,000	31,600	76,300	126,100	181,500	243,000	287,800
	35,000	33,900	86,000	144,000	208,400	280,100	332,200
	40,000	36,200	95,600	161,700	235,100	316,500	375,800
	45,000	38,500	105,200	179,400	261,900	353,500	420,100
	50,000	40,800	115,000	197,500	289,000	390,700	464,500

Table 18

		Years before benefit					
	$ 420,100	1	4	7	10	13	16
Discount rate	5%	367,400	406,200	377,900	308,700	231,800	146,400
	10%	148,300	164,000	152,500	124,600	93,600	59,100
	15%	62,300	68,900	64,100	52,300	39,300	24,800
	20%	27,200	30,000	27,900	22,800	17,100	10,800
	25%	12,300	13,500	12,600	10,300	7,700	4,900

Table 19

111. In addition to facilitated SDM resulting in someone moving from a more intensive to a less intensive congregate care setting, a person using facilitated SDM may reduce their likelihood of needing more intensive congregate care as they age. This scenario would also result in a positive net present value to New York.

Estimated Present Value of Lump Sum

112. Stout also estimated a lump cost savings to New York for all 500 expected Decision-Makers per year. Each of the 500 Decision-Makers will have different levels of generalized service use, delayed entry into congregate care, and use of the emergency department (as demonstrated in the scenario analyses). Stout used publicly available information and the expertise of SDMNY to develop an estimate as to the total annual cost savings for all 500 Decision-Makers in these three cost categories.

113. Delayed Entry into Congregate Care. Of the 500 Decision-Makers, an estimated 27% will likely delay entry into congregate care.[132] At an average annual cost of $65,000 per person[133] for congregate care, New York could realize cost savings of approximately $8.8 million annually through delayed entry into congregate care.

[132] "Cost Benefit Analysis of Supported Decision-Making." Bulgarian Center for Not-for-Profit-Law. 2014.
[133] Estimated by Stout using data from OPWDD indicating that approximately $3.9 billion was spent to provide supervised residential habilitation services to approximately 30,000 people in 2019, and New York is responsible

114. **Decreased Use of Generalized Services.** Of the 500 Decision-Makers, 100% would be expected to decrease their use of generalized services, based on the experience and expertise of SDMNY. At an estimated average annual cost of $16,000 per person[134] for generalized services and an expected cost reduction of 8%,[135] New York could realize cost savings of approximately $640,000 annually through decreased use of generalized services.

115. **Decreased Use of Emergency Room.** Of the 500 Decision-Makers, an estimated 34% would use emergency room services less frequently.[136] The per visit cost of visiting the emergency room is $420, and an estimated 3 emergency room visits would be avoided.[137] New York could realize cost savings of approximately $210,000 annually through decreased emergency room use.

116. **Present Value of Estimated Lump Sum Savings.** Stout estimated total potential annual cost savings to New York of $9.6 million ($8.8 million in delayed congregate care entry, $640,000 in decreased use of generalized services, and $210,000 in decreased use of emergency room services). Using a 5% discount rate and a 20-year period (consistent with the scenario analyses), the present value of the future $9.6 million in annual savings to New York is an estimated $119.9 million for 500 PWDD using facilitated SDM. With an annual investment of $3.5 million from New York in facilitated SDM and an estimated annual cost savings of $9.6 million, the return to New York per dollar invested is $2.75.

Conclusion

117. Facilitated SDM has not been extensively studied in the United States, and data regarding potential cost savings to states with facilitated SDM does not currently exist. However, research does indicate that when PWDD make decisions on their own, often with support

for 50% of the cost of these services. Stout estimated the cost of less intensive congregate care using data from OPWDD indicating that approximately $81 million was spent for less intensive supportive care for approximately 2,000 at an estimated cost of $40,000, of which New York is responsible for 50% ($20,000 per person).

[134] Estimated by Stout using data from OPWDD indicating that approximately $1.4 billion was spent to provide day habilitation services to approximately 45,000 people in 2019. New York's portion is 50%.

[135] Head, James and Conroy, Michael. "Outcomes of Self-determination in Michigan: Quality and Costs." In Stancliffe and Lakin, Costs and Outcomes of Community Services for People with Intellectual Disabilities. 2005.

[136] Durbin, Anna et al. "Emergency Department Use: Common Presenting Issues and Continuity of Care for Individuals With and Without Intellectual and Developmental Disabilities." J Autism Dev Disorder. October 2018.

[137] "Trends in Utilization of Emergency Department Services, 2009-2018." U.S. Department of Health and Human Services Office of the Assistance Secretary for Planning and Evaluation. March 2021.

from trusted people in their lives, they are able to live more independently and may use fewer Medicaid services.

118. Stout considered a variety of scenarios where facilitated SDM would likely result in congregate care, emergency department care, and generalized services cost savings. The scenarios that Stout considered also considered the few situations where facilitated SDM may cost more than the benefits derived. Stakeholders throughout New York indicated that these scenarios would exist but also acknowledged that they would be uncommon. Stout analyzed three primary scenarios where facilitated SDM experts in New York would expect PWDD to use facilitated SDM:

    - Scenario 1: Achieving an Exit from Congregate Care;
    - Scenario 2: Delaying Entry into Congregate Care;
    - Scenario 3: Decreased Use of Emergency Department Care and Generalized Services; and
    - Scenario 4: Decreased Use of Intensive Congregate Care.

119. In Scenarios 1, 2, and 4, Stout also considered potential reductions in emergency department care and generalized services use. Assuming a reasonable distribution of scenario outcomes, Stout estimates that New York would experience a significant positive net present value of facilitated SDM even after accounting for the cost of facilitated SDM. Stout also calculated the present value of lump sum savings that may be attributable to the annual 500 Decision-Makers. The present value of lump sum savings related to delayed congregate care entry, decreased use of generalized services, and decreased use of emergency services is an estimated $119.9 million, calculated used a 5% discount rate and a 20-year period. With an annual investment of $3.5 million from New York in facilitated SDM and an estimated annual cost savings of $9.6 million, the return to New York per dollar invested is $2.75.

120. Stout's estimate of the economic benefits realized by New York through facilitated SDM are likely significantly understated. Included in the calculation are benefits of facilitated SDM that are quantifiable and reasonably reliable with available data. However, if PWDD experienced more empowerment, autonomy, self-determination, and the dignity of risk, New York would enjoy many benefits that are not at this time reliably quantifiable and therefore are not included in Stout's calculations. The benefits that would be enjoyed by New York include, but are not limited to:

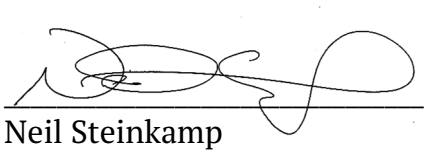
    - Increased self-determination, independence, empowerment, inclusion, and dignity (including the dignity of risk) for PWDD;

- Increased quality of life for PWDD;
- A reduction, over time, of the number of guardianship cases filed resulting in improved use of New York court resources;
- Increased wages and gainful employment opportunities for PWDD;
- Decreased physical health expenditures and usage of emergency room services;
- A reduction in the administrative costs and use of resources associated with health care providers and banking institutions, for example, attempting to determine if a person with IDD has capacity to make a decision;
- Increased likelihood of being enrolled in formal education;
- Improved efficiency in OPWDD services from a reduction of thet need to rely on surrogates for consent required under federal and state rules;
- A reduction in the number of PWDD interacting with law enforcement, incarceration costs for PWDD, other criminal system costs necessary for adjudicating a case, and the likelihood of recidivism;
- Increased likelihood of successful re-entry following incarceration; and
- Reduced concern among, and pressure on, parents and caretakers seeking to ensure the long-term safety of their loved ones.

Assumptions and Limiting Conditions

121. Stout's conclusions are based on information received to date. Stout reserves the right to change those conclusions should additional information be provided.

122. Stout's review, research, and analysis was conducted on an independent basis. No one who worked on this engagement has any known material interest in the outcome of the analysis.



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Appendix
Additional Research

Housing

1. In 2011, New York Governor Andrew Cuomo found that the state-funded portion of Medicaid was increasing at an unsustainable rate and resulting in unsatisfactory health outcomes for beneficiaries.[138] Governor Cuomo signed an executive order creating the New York Medicaid Redesign Team (MRT), which was tasked with examining Medicaid-related practices and developing a plan for reforming New York's Medicaid program.[139] MRT found that the state's Medicaid system led to an "over-reliance on State psychiatric hospitals, adult homes and nursing homes."[140] The reason for this being a lack of affordable housing for people who do not need institutionalized care and because integrated, community-based housing is unavailable for people needing supportive services.[141] This situation results in beneficiaries receiving incomplete health care for their needs and in turn, experiencing poorer health outcomes.[142] Housing beneficiaries who do not require intensive services in institutions increases state Medicaid costs, which are significant – between approximately $120,000 and $180,000 per person per year in New York City.[143] The cost of institutionalized care may be up to three times higher than non-institutionalized care.[144]

Incarceration of PWDD and Formerly Incarcerated PWDD

2. PWDD are overrepresented in the criminal system. PWDD are also a high percentage of people (along with people who have psychosocial disabilities) who are incarcerated whose sentences are not reduced by time for good behavior. Instead, PWDD frequently "max-out," serving their full sentences potentially with time in segregation or otherwise punitively barred from rehabilitative services available to the general prison population. When their sentences end, PWDD are given a small sum of money and transported via bus back to the city from which they came without a support system or adequate skills or practice to make decisions about their lives. Unsurprisingly, a portion of this population recidivates and returns to the criminal system.

3. The current interest in re-entry programs has not focused on PWDD, but a small pilot project funded by the New York Community Trust is exploring ways to utilize the year pre-

[138] "East Harlem, New York: Supporting Affordable Living and Health Care as Part of State Medicaid Redesign." Office of Policy Development and Research, U.S. Department of Housing and Urban Development. 2016.
[139] Ibid.
[140] "MRT: Behavioral Health Reform Work Group Final Recommendations." New York State Department of Health. October 2011.
[141] "East Harlem, New York: Supporting Affordable Living and Health Care as Part of State Medicaid Redesign." Office of Policy Development and Research, U.S. Department of Housing and Urban Development. 2016.
[142] Ibid.
[143] Ibid.
[144] Ibid.

release to build the resources necessary to avoid recidivism and re-institutionalization and the associated costs. Teaching PWDD how to make decisions, use supports in making them, and create a support network could be an effective addition to re-entry programming, and SDMNY is hoping to offer facilitated SDM as a part of the pilot. While determining actual results will take time, it is reasonable to expect that at a portion of PWDD who learn to use facilitated SDM and who become more self-determined and socially connected as a result will have better outcomes. According to a 2015 Vera Institute study, the annual marginal cost per incarcerated person in New York State-funded prisons is approximately $18,700.[145] That is, when the prison population in New York State-funded prisons decreases by one person, the state saves approximately $18,700 annually. Considering that approximately 43% of people released from New York State Department of Corrections and Community Supervision are reincarcerated within three years, facilitated SDM could, over time, reduce recidivism-related incarceration costs to New York.[146] Based on Stout's interviews with stakeholders in New York, facilitated SDM may be beneficial for PWDD who are re-entering society after incarceration. Many people re-entering society face challenges securing housing, employment, and health care, particularly if they have IDD. Facilitated SDM can provide the support necessary for PWDD who are re-entering society to live independently, gain employment, and make decisions about their health care services. Stakeholders indicated that if these outcomes were achieved through facilitated SDM, there is a high likelihood of reducing recidivism for this population.

4. Although not based on recidivism, one of the few studies on the cost savings of facilitated SDM is related to people who have been incarcerated while awaiting trial and suggests this as an area of cost savings. A 2017 Australian study found that models of support for PWDD interacting with the criminal system can improve the timeliness and quality of legal outcomes for PWDD and result in cost savings related to police, courts, and incarceration.[147] The researchers detailed a case study where they found that a person with IDD who was supported through their criminal proceedings was able to have criminal charges against them withdrawn (as a result of their supporter working with their defense attorney and the prosecution) and costs to the court were reduced to approximately $5,000 ($AUD). This outcome was compared to two other likely outcomes had the person with IDD not been supported through the criminal proceedings. The first alternative was that the person with IDD would have been deemed unfit to stand trial which could have resulted in one of following criminal system costs (all in $AUD and all annual costs), depending on the outcome of the case: approximately $400,000 in incarceration costs; approximately

[145] Mai, Chris and Subramanian, Ram. "The Price of Prisons: Examining State Spending Trends, 2010-2015." Vera Institute of Justice. May 2017.
[146] "2014 Inmate Releases Three Year Post-Release Follow-Up." New York State Department of Corrections and Community Supervision. 2014.
[147] McCausland, Ruth, et al. "The economic case for improving legal outcomes for accused persons with cognitive disability: an Australian study." International Journal of Law in Context. 2019.

$90,000 in supervision order costs; or approximately $70,000 in acquittal costs.[148] The second alternative was that the person with IDD could have entered a guilty plea (via their lawyer) to avoid unfitness-to-stand-trial proceedings which could have resulted in one of the following criminal system costs (all in $AUD and all annual costs), depending on the outcome of the case: approximately $130,000 in incarceration costs; approximately $50,000 in community order costs; approximately $15,000 in modified community order costs; or approximately $10,000 in conviction costs without a penalty.[149] For these alternative outcomes, the cost to the criminal system ranges from $10,000 to $400,000 – between two and 80 times more than the cost to the criminal system were the person with IDD supported through their proceedings. The Australian study indicates that,

> "without [supporters], people with cognitive disabilities may face the relatively rare but highly problematic prospect of indefinite detention after being found unfit to stand trial or the more common likelihood of serial detention, incarceration and community supervision… the strategic support to improve the accessibility of criminal proceedings reduced the need for unfitness-to-please determinants under current law by assisting accused persons to participate in proceedings and exercise their legal capacity."[150]

[148] Ibid.
[149] Ibid.
[150] Ibid.