

## **Principles for an Initial Supported Decision-Making Agreement (SDMA) Law**

### **Introduction: Supported Decision-Making and Supported Decision-Making Agreements**

Everyone has a right to make their own decisions. Everyone makes decisions, both big and small, with support from others. People with disabilities may need more or different kinds of support, but their decisions should be entitled to legal recognition on an equal basis with all other people.

Supported decision-making (SDM) is something we all do, but in the context of people with disabilities, it is

“a series of relationships, practices, arrangements and agreements of more or less formality designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”<sup>1</sup>

SDM may be entirely informal, as it currently is for the many people with disabilities who are not subject to guardianship, but who rely on family, friends and care workers to support them in their decisions. It may be more specific, as in “circles of support” used in, for example, Self-Direction of Medicaid Home and Community Based Waiver Services (HCBS). Or it may be more formalized, utilizing a Supported Decision-Making Agreement (SDMA) in which the person with a disability (the Decision-Maker) denominates trusted persons in their life (the Supporters) to give them support, in specified ways, on decisions in specified domains.

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<sup>1</sup> Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 Hum. Rts. Brief 8, 10 (2012)

Finally, SDM and SDMA may be legally recognized by statutes (SDMA statutes) in which the legislature requires third parties to accept decisions made pursuant to them on an equal basis with all others; as such, SDMA statutes are, first and foremost, *anti-discrimination laws*. Although, as noted below, statutory recognition of decisions made pursuant to SDMA has important implications for guardianship, particularly the reasons it may be sought, SDMA statutes do not abolish guardianship or affect the existing processes by which guardianship may be sought or imposed.

SDMAs are important for a number of reasons. Because of deep-seated stigma and discrimination against people with developmental<sup>2</sup>, cognitive and psychosocial disabilities, third parties, such as health care providers, financial institutions, etc. may refuse to accept their decisions based on a belief that they lack “legal capacity.” Such third parties may insist that someone obtain legal guardianship, resulting in loss of the person’s civil and legal rights, as a condition of providing the health care, approving the transaction, etc. Concern about this happening to their adult children with disabilities pushes parents to seek guardianship when those children reach their majority, regardless of their children’s decision-making capabilities. Legislative recognition of decisions made pursuant to SDMA overcomes this discrimination, and avoids unnecessary guardianships and the resulting loss of civil and legal rights.

SDMAs are also powerful statements by Decision-Makers of how they choose to make their decisions, affirmations of their right to do so, and advocacy tools as they make their way through a world which still, 30 years after passage of the Americans with Disabilities Act (ADA), is rife with discrimination that deprives them of equality of treatment and opportunity. As such, formal/legal recognition of decisions made pursuant to SDMA promotes their autonomy, self-determination and inclusion, and moves us all toward a more just society.

### **Toward an Initial SDMA Statute in New York: DDPC, SDMNY and Draft Principles from a Five-Year Pilot Project**

Since 2014, a number of states—Texas, Delaware, Wisconsin, Alaska, Indiana, Nevada, Rhode Island, North Dakota, Washington and Louisiana—as well as the District of Columbia, have passed statutes recognizing SDM and SDMA. Several other states, including Massachusetts, Virginia and Illinois have SDMA statutes in the legislative pipeline or under active consideration. With the possible exception of Massachusetts, none of these laws were based on any empirical evidence of how SDM works or for whom. As to persons with DD, although not yet to those

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<sup>2</sup> A note about language. While New York’s guardianship statute, N.Y.S.C.P.A. Sec. 1750 and 1750-a refer separately to persons with an “intellectual disability” (replacing the prior term “mentally retarded”) and a “developmental disability” (defined as including persons with cerebral palsy, epilepsy, neurological disorder, autism or traumatic head injury), “developmental disability”(DD) has become the “umbrella term” for both, see e.g. American Association on Intellectual and Developmental Disabilities, Frequently Asked Questions on Intellectual Disability, [www.aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability](http://www.aaid.org/intellectual-disability/definition/faqs-on-intellectual-disability), and is employed by both the NYS Office of People with Developmental Disabilities (OPWDD) and the NYS Developmental Disabilities Planning Council (DDPC), and is used throughout these Principles to cover both groups.

with psychosocial and cognitive disabilities, New York State has taken a different, more thoughtful and grounded approach.

Here it is important to note that although existing empirical work has thus far been limited to people with DD, the experience and learnings from that work is not intended in any way to limit the use and availability of SDM and SDMA to people with other disabilities whose legal capacity may be questioned and/or curtailed, including by guardianship.

In 2016, the NYS Developmental Disabilities Planning Council (DDPC) awarded a five-year grant to Supported Decision-Making New York (SDMNY), a consortium of Hunter College/CUNY, the New York Alliance for Inclusion and Innovation (a statewide association of provider agencies, formerly NYSACRA) and The Arc Westchester, to design and pilot SDM and SDMA, both to divert persons with developmental disabilities (DD) at risk of guardianship from guardianship, and to restore rights to people with DD currently subject to guardianship. In the ensuing years since, it has done that, expanding from its original site in New York City to sites in Albany/Capital Region, Long Island, Rochester/Western New York, and Westchester, and enrolling more than 135 Decision-Makers who reflect the racial, ethnic, gender and gender identity, economic and geographic diversity of New York State.

As a pilot project, SDMNY has employed a number of strategies, and generated important learnings.<sup>3</sup> Primary among them is that SDM is a *process* that Decision-Makers and their Supporters need to learn and practice, that it takes time, and that to be meaningful, an SDMA must be more than a form or piece of paper signed by the Decision-Maker. Instead, it should reflect the process of decision-making with support that the parties have worked toward and agreed upon, and that is intended to serve the Decision-Maker going forward with their life. To accomplish this goal, and based on pilot projects and research from around the world, SDMNY has developed a three-phase facilitation process, through which Decision-Makers and their chosen supporters learn about and practice SDM with the assistance of a trained facilitator who, in turn, is supported by an experienced mentor.<sup>4</sup> All parties, Decision-Makers, Supporters and Facilitators describe the SDMNY facilitation process as transformational, not only resulting in an SDMA with integrity, but also empowering the Decision-Makers and promoting their self-determination and autonomy.

The DDPC grant also called for an education campaign about SDM for diverse groups of stakeholders in the DD community, which, combined with the results of the pilot program, was expected to form the base for an SDMA statute for persons with DD in New York. SDMNY has

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<sup>3</sup> See, e.g., Kristin Booth Glen, *Supported Decision-Making from Theory to Practice: Further Reflections on Four Years of an Intentional Pilot Project*, 13 Albany Government L. Rev. 94 (2020); Kristin Booth Glen, *Piloting Personhood: Reflections from the First year of a Supported Decision-Making Pilot Project*, 39 Cardozo L. Rev. 495 (2017)

<sup>4</sup> For a more detailed description of the facilitation process, see <https://sdmny.hunter.cuny.edu>

met this requirement, educating stakeholders, and initiating conversations about the need for SDMA legislation, and what the SDMNY experience can bring to that conversation.

Although that conversation has been primarily directed to persons with DD, their families, service providers, and educators, efforts to further advance SDM and make SDMA legislation more inclusive need to take into account persons with psychosocial disabilities, older persons with cognitive decline, dementia, etc., and those with dual diagnoses, whose right to make their own decisions with support is no less, and no less worthy of attention.

Over more than a year, SDMNY convened a Legislative Working Group (LWG) from among members of its diverse Advisory Council (AC) of stakeholders to draft “Principles” for potential SDMA legislation in New York. The initial LWG draft, the result of a number of meetings, was then circulated to the entire AC for comments. After some additions and revisions, the draft was further vetted through six focus groups of parents, including a Spanish language group, convened by NYS Parent to Parent, and six geographically diverse groups of people with DD convened by the Self-Advocacy Association of New York State (SANYS), and circulated to other stakeholder organizations. What follows are “Principles” for an SDM and SDMA statute generally, and then for the specific provisions that would, as a first step, extend legislative recognition to decisions pursuant to SDMAs made by people with DD.

## **Principles Regarding SDM and SDMA Laws**

### **Introductory Principle regarding an initial SDMA Law for New York**

***A statute that provides legal recognition for SDMAs should initially apply to persons with developmental disabilities, while affirming the right of all persons to use SDM and to make their own SDMAs***

We all have the right to make our own decisions, and to have the support necessary to do so, regardless of disability. This is a human right, as recognized by the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Although the United States has not ratified the CRPD, this right should provide inspiration that guides legislation around SDM and SDMAs.

While SDM and legal recognition of SDMAs should be available for all persons with developmental, psychosocial and cognitive disabilities, there is no single model of how SDM works, or could work, for members of these different groups—people with DD, with mental illness, older persons with Alzheimers, dementia, etc. Most of the now-considerable empirical evidence from SDM pilot projects around the world has focused on people with DD; this is also the case in the US, with New York’s pilot, SDMNY, being the largest, most thorough and extensive. The results of those pilots and relevant academic research have resulted in general consensus on a model that uses a facilitation process for persons with DD and their Supporters. There is now knowledge, information and experience about how to support decision-making for persons with DD arguably sufficient to confer legislative recognition—and the accompanying

immunity from liability for third parties—on decisions made pursuant to SDMA made by individuals with DD who have used a facilitation process. Members of other groups also may benefit from SDMA. The evidence base for how those SDMA can be formed, and the service-provision structure that would best support SDMA for other groups is still developing, but so far lacks any comparable consensus about what actually works.

We hope that the work done by SDMNY and others will encourage similar, empirical work on SDM for older persons with cognitive decline, and for those with mental illness and traumatic brain injuries (TBIs). While there are clearly synergies, SDM and getting to an SDMA is not a “one size fits all” process. A statute that recognizes and legalizes decisions made pursuant to SDMA for persons with DD, and the benefits it will bring, should provide an important impetus for work that could ultimately lead to greater autonomy and self-determination for persons with other disabilities whose legal capacity may be challenged or curtailed, including through guardianship. Passing an SDMA statute for people with DD should be, and should be recognized as *only the first step in promoting and protecting the right of all people with disabilities to make their own decisions with the support they need and desire*, and to have those decisions legally recognized.

For these reasons, the “Principles” for legislation that follow are divided into two sections, the first, A., which should be applicable to SDM and SDMA generally, regardless by whom they are made, and not confined to persons with DD. They are intended to acknowledge and encourage the use of SDM and SDMA, and to provide general, non-binding guidance. The second section, B., provides principles for the specific aspects of an “initial” New York statute that would confer legal recognition on decisions made pursuant to SDMA made by people with DD.

## **A. General Principles for an initial statute recognizing SDM and SDMA**

### **I. SDM and SDMA should be defined in easily understandable and non-exclusive terms**

SDM can occur in many ways and in many settings, and any statute should both recognize and encourage the variety of ways in which people with disabilities use supports to make decisions, including entirely informal support networks as, for example, courts have done in denying or terminating guardianships.

For example, the Indiana statute defines SDM as

“the process of supporting and accommodating an adult in the decision-making process to make, communicate and effectuate life decisions without impeding the self-determination of the adult”

while recognizing a more formalized process resulting in an SDMA , defined as

“a document that outlines the decision-making supports and accommodations the adult

chooses to receive from one (1) or more supporters”

- II. **Everyone should be able to make an SDMA, and there should be no negative consequences for doing so. No one should be prevented from making an SDMA based on traditional definitions of “capacity” that discriminate against persons with disabilities**

People should be encouraged to make SDMAs, and the fact that someone chooses to make an SDMA should not be used against them in any way. Existing statutes note and provide for this in several ways including specific prohibitions on using the existence of an SDMA as evidence of incapacity, or denying benefits to which the person is otherwise entitled. Similarly, no one should be required to sign an SDMA in order to access necessary services.

The fact that a Decision-Maker has signed an SDMA should not obligate her/him to use it in making any particular decision, and s/he remains free to make decisions in any way she chooses.

The law already provides that every adult not under guardianship is presumed to have legal capacity. This presumption extends to the capacity to make an SDMA regardless of disability and any SDM/SDMA statute should make that explicit.<sup>5</sup>

Because the meaning of legal capacity varies depending on the action to be taken or the transaction to be undertaken, legal capacity to make an SDMA requires only that the person understand that s/he is making an agreement with her/his chosen supporters, and that s/he is doing so voluntarily.

Any determination of capacity to make an SDMA must include capacity *with support*.

- III. **A person’s use of SDM and/or making an SDMA should be considered by courts as evidence of a “less restrictive alternative” to guardianship regardless of their disability and whether their SDMA is one which requires legislative recognition for decisions made pursuant to it.**

An SDMA statute does not abolish guardianship or preclude anyone, parents or others, who would be entitled to commence guardianship proceedings under existing statutes from doing so. Nor, however, should it affect the existing standards for imposing and/or continuing guardianship. New York courts have already begun to consider the use of informal SDM as a

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<sup>5</sup> If capacity to enter into an SDMA is questioned, the presumption of capacity for all adults, including those with disabilities, should only be rebutted by clear and convincing evidence, and a diagnosis of psychosocial disability, TBI, or progressive cognitive decline (Alzheimers, dementia, etc.) alone does not meet that standard.

basis for denying guardianship<sup>6</sup> or restoring rights to persons subject to guardianship<sup>7</sup> under the constitutionally required principle of “least restrictive alternative.”<sup>8</sup> Just as these Principles recognize everyone’s right to use SDM and to make SDMA, it should be clear that enactment of a statute legislatively recognizing decisions made pursuant to SDMA made through a particular, recognized process is not intended to limit courts considering all kinds of decision-making supports as “less restrictive alternatives”.

Similarly, initial legislative recognition of decisions made by persons with DD pursuant to a facilitated SDMA should not preclude appropriate judicial consideration of, and reliance on, evidence of the use of SDM and SDMA by persons with other disabilities, including older persons with cognitive decline, dementia, Alzheimers, etc., persons with TBIs and persons with psychosocial disabilities.

#### **IV. Persons making SDMA, the “Decision-Makers,” have the sole right and power to choose the areas in which they want support, the kinds of support they want, and the person(s) from whom they want that support**

An SDMA will typically contain the Decision-Maker’s choices as to the domains in which support is requested, the persons they choose to provide support in each of those domains (the “Supporters”), and the specific kinds of support they wish from each Supporter in each domain. Existing SDMA statutes generally list common domains, such as health care, education, housing, etc., which may be useful in a nonexclusive SDMA form or template. Any such list, however, should not limit the areas a Decision-Maker may choose; SDMNY’s experience shows that there are almost as many areas in which support is desired as there are Decision-Makers.

Similarly, statutes (and statutory forms) may list kinds of decision-making support, which generally include: gathering information; assisting in understanding information; identifying alternatives; considering the consequences of making—or not making—the decision; weighing alternatives; communicating the decision to others (especially important for persons who do not communicate in traditional ways); and implementing the decision. Decision-Makers should be free to choose commonly listed supports, but also to request more specific or nuanced kinds of support, as SDMNY experience has demonstrated. SDMNY has also learned that it is important to be clear that the kinds of support given in SDMA are for *making decisions*, not for achieving goals or other concrete results.

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<sup>6</sup> See, e.g., *Matter of Zachary W.*, 2017 NYLJ LEXIS 1107 (Sur. Ct. Suffolk Co. 2017); *Matter of Michelle M.* 2016 NYLJ LEXIS 2719 (Sur. Ct. Kings Co. 2016).

<sup>7</sup> See, e.g., *Matter of Capurso*, 63 Misc. 3<sup>rd</sup> 725 (Sur. Ct. Westchester Co. 2019); *Matter of Dameris L.*, 38 Misc.3<sup>rd</sup> 570 (Sur. Ct. NY Co. 2012).

<sup>8</sup> See, e.g. *O’Connor v. Donaldson*, 422 U.S.563 (1975); *Kesselbrenner v. Anonymous*, 33 N.Y. 161,165 (1973); *Manhattan Psychiatric Center v. Anonymous*, 285 A.D. 2d 189, 197-98 (1st Dept. 2001)

It is also critical to the integrity of any SDMA that the choice of Supporters be solely that of the Decision-Maker, with no or minimal limitations on who can serve as a Supporter. Some existing SDMA statutes bar certain classes of persons from serving as Supporters, but overbroad limitations can both constrain the Decision-Maker's right to choose and also limit or deprive her/him of the ability to obtain support altogether. For example, some statutes disqualify employees of agencies or other providers from whom a person receives services, but for some Decision-Makers without family or other natural supports, trusted staff members may be the only persons available. Similarly, given the current understanding of the existence of systemic racism in the criminal justice system, blanket disqualifications on persons who have been convicted of a crime, however long ago, may have a disparate impact on minority Decision-Makers' ability to choose their Supporters. One limited, possibly acceptable exception that exists in some statutes, is disqualification of any person against whom there is or has been an Order of Protection against the Decision-Maker.

In order to provide support for decisions in certain areas, like health care and education, the Supporter(s) may need access to the Decision-Maker's otherwise confidential records, and SDMA statutes generally provide for such access, though additional documents (such as HPPA and FERPA releases) may be necessary; these should be specifically referenced in the statute. It should be clear, however, that choosing a Supporter for health care, educational or financial decisions does not automatically confer authority to access relevant records of that person. Supporters who are given access should owe a duty of confidentiality to the Decision-Maker with respect to such records.

**V. A decision made pursuant to an SDMA can only be made by the Decision-Maker, and not by Supporters, and only the Decision-Maker is responsible for the decision**

Existing law provides for a number of ways an adult can delegate decision-making to a third party, including Powers of Attorney and Health Care Proxies. Making an SDMA does not preclude use of those instruments, which can coexist with an SDMA, but a Supporter may not make a decision *for* the Decision-Maker under the SDMA, nor does the Supporter have any independent legal status. The Decision-Maker is solely responsible for decisions made pursuant to an SDMA and, accordingly, Supporters cannot be held liable for the consequences of such decisions. This immunity is important in order to lower barriers to entry that might prevent prospective Supporters from agreeing to sign on to SDMAs, as well as to provide clarity to third parties about who is ultimately responsible for decisions.

**VI. Supporters should respect the right of Decision-Makers to make their own decisions and should not engage in substitute decision-making, undue influence or conflict of interest**

SDM is specifically intended to avoid substitute decision-making, whether informal paternalism, or legally imposed guardianship, that gives decision-making authority to another. Supporters need to be clear about what it means to support another's decision, not to make it for them,



even when they disagree. Nor should they attempt to unduly influence the Decision-Maker, and they should avoid conflicts of interest. Acknowledgement of these obligations, such as that included in the Supporters' signed affirmation in the SDMNY SDMA template, should be required.

### **VII. The Decision-Maker can change or revoke the SDMA at any time**

Circumstances change and Decision-Makers should have the unfettered right to change their SDMAs as they choose. This might involve removing an area for support as the Decision-Maker gains capability and confidence; adding an area as the Decision-Maker's life expands to include more and/or different kinds of decisions; removing or adding Supporters; or terminating the SDMA altogether.

Because only Decision-Makers can make binding decisions under an SDMA and the Supporters are only there to support them, unlike a Power of Attorney, there is no need for notice of change or revocation to third parties. An amended or revised SDMA should, however, be made with the same formalities as the original SDMA and should be shared with all remaining Supporters. Revocation can be made physically or by written instrument. If there is more than one SDMA, covering the same kinds of decisions/domains, the SDMA dated later in time should prevail.

### **VIII. There should be only modest formalities required for execution of an SDMA**

To encourage people to make SDMAs, there should be no unnecessary barriers or requirements such as notarization, which may create misapprehension that it serves as a guarantor of capacity, as opposed to verification of the identity of those signing the agreement. However, in order to demonstrate the integrity of the execution to third parties, and to impress the seriousness and importance of the SDMA on all parties, as with execution of a will, SDMA execution should be witnessed by two adults (persons 18 or over). Witnesses to an SDMA should be able to understand the Decision-Maker's mode of communication, and should not, themselves, be parties to the SDMA (i.e. Supporters).

### **IX. Because guardianship is a significant or total deprivation of a person's liberty and/or property rights, and less restrictive alternatives must be considered before guardianship can be imposed, relevant state actors should make information about SDM and SDMAs available, including in plain language**

SDM is now widely recognized as an appropriate and effective alternative to guardianship by federal and state agencies including the National Council on Disability (NCD), the Administration for Community Living (ACL), the New York State Office for People with Developmental Disabilities (OPWDD), the American Bar Association, the Uniform Law

Commission, ARC of the US, the National Guardianship Association, etc., at the same time that consideration of less restrictive alternatives is constitutionally required, and included in many guardianship statutes.

Studies, anecdotal information, and the experience of SDMNY have all shown that, while parents of young, transition-age adults have been informed about guardianship over many years, and from many sources, most are unaware that there may be less-restrictive alternatives for their children with DD, and are completely unaware of SDM and SDMA. Federal law requires schools to engage in “transition planning” for young adults aging out of services provided by the education system, and while such transition planning has historically included and/or focused on parents obtaining guardianship, information about SDM has generally been missing.<sup>9</sup> Schools should be required to offer such information as part of their mandated obligation under the IDEIA to provide planning to prepare students “to lead productive and independent adult lives...,” and at least one proposed SDMA statute imposes such requirement.

The majority of guardianships for persons with DD, both transition age and older, are pursuant to Article 17-A of the Surrogates Court Procedure Act, and take place in the Surrogates’ Court. Information about SDM and SDMA should be available in all Surrogates Court Clerks’ offices (or Guardianship Clerks’ offices in larger counties where there are such specialized departments), as is already the case in a number of counties, and, as well, on the official Surrogates’ Court website. It should also be made available on the DIY portion of the N.Y.S. Courts’ website, which provides information about 17-A proceedings and assists potential petitioners in generating court papers.

The availability of information about SDM is important not only for parents dealing with transition planning in the education system and potential petitioners for Article 17-A guardianship, but most critically for persons with DD themselves, and so should be made available in Plain Language format.

Because people with disabilities other than DD should also be encouraged to use SDM and make SDMA as an alternative to guardianship, even if those SDMA are not yet granted legislative recognition, information about SDM should be made available in the Clerks’ offices in Supreme Court, where Article 81 guardianships are commenced. Finally, public agencies that deal with persons with developmental, cognitive and psychosocial disabilities, like OPWDD, OMH, etc., should have and make information on SDM and SDMA readily available.

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<sup>9</sup> See Arlene S. Kanter, Carrie Rood, Julie Causton, *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process* (with Carrie E. Rood and Julie Causton), 39(4) RESEARCH AND PRACTICE FOR PERSONS WITH SEVERE DISABILITIES 319 (2015); Arlene S. Kanter, *Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act*, 8 JOURNAL OF INTERNATIONAL AGING LAW AND POLICY 1 (2015).

## **B. Principles for legislative recognition and third-party obligation to honor SDMAs**

Supported decision-making can serve as an alternative to guardianship with or without a statute governing SDMAs. The benefit of a statute recognizing a particular kind of SDMA is that it can impose a legal obligation on third parties to accept decisions made pursuant to the SDMA and, in return, grant corresponding immunity from liability for good faith acceptance. That grant of immunity from liability for good-faith acceptance requires additional consideration by lawmakers, including some level of confidence that the SDMA reflects a decision actually made by the Decision-Maker with the support s/he has chosen.

There is no need to confer legislative recognition on decisions made pursuant to SDMAs made by persons who do not currently have disabilities. They are legally presumed to have capacity and, unlike people with developmental, psychosocial or cognitive disabilities, that capacity is unlikely to be questioned by third parties. An SDMA describes how a Decision-Maker/person with DD makes their decisions with support, and, among other purposes, is intended to demonstrate adequate functional capacity (individual capability plus support) to third parties, who should be encouraged to accept and honor the person's decisions. Whether because of ignorance, stigma, discrimination or fear of potential litigation, however, they may not always do so.

Requiring recognition and acceptance *by law*, as an increasing number of jurisdictions in the US have already done, is necessary to ensure that the decisions of persons with disabilities who have executed SDMAs will be honored by third parties, without regard to disability. Of necessity, a law providing statutory recognition—an SDMA statute—requires additional provisions to give notice as to *whose* SDMAs are covered, the form or necessary inclusions of covered SDMAs, the formality with which they are executed, the precise obligation or obligations, including reporting, of third parties who are asked to rely on them, the scope of immunity granted to the complying third party and the requirements, if any, of the *process* by which the SDMA was reached.

What follows are the additional principles we believe New York should incorporate in an “initial” SDMA statute for people with DD, with the clear understanding that, as further work is done to develop and use decision-making supports for other groups, including older persons with cognitive decline, persons with TBIs and persons with psychosocial disabilities, legislatively compelled recognition should be extended to SDMAs executed by members of those groups as well.

***In order to receive legal recognition,***

- X. SDMAs should be in a form, or using a template, authorized by the legislature, but**

**Decision-Makers and their Supporters should be able to vary or modify the form/template so long as the SDMA substantially complies with its terms and provisions**

SDMNY has found that it is helpful to Decision-Makers and their Supporters to have a template they can utilize in memorializing their agreements about the areas in which support is desired, by whom it is given, and what kinds of support each Supporter is to give in any area for which s/he is chosen to support the Decision-Maker. (See Principle III above.) The SDMNY template was developed after consideration of numerous pilot-project templates and statutory forms, with consultation and input from stakeholders, especially including self-advocates.

It is important, however, that any template or statutory form provide only an approved, but not required, model. The parties should retain the ability to vary or modify it, or even to create their own form, so long as its contents substantially comply with any statutory form. For clarity, an SDMA statute should enumerate a limited number of essential elements for a valid SDMA to ensure consistency and the ability to be recognized by third parties.

Because the Decision-Maker is not legally bound to follow the process contained in the SDMA (**Principle II**), it should, however also include, as an attachment, a standardized form by which the Decision-Maker attests that a particular decision has been made utilizing the relevant support(s) set forth in the SDMA. A third party may request such attestation before they are obligated to accept and honor that decision. Because there is no need for individualization of such form, standardization is appropriate and useful for more ready acceptance by third parties.

**XI. SDMAs should be signed in the presence of two adult witnesses who are not themselves parties to the agreement, and who understand, with support if necessary, the Decision-Maker's chosen means of communication**

For legislative recognition, there should be a level of formality that confirms that the Decision-Maker and Supporters actually signed the SDMA (although signature[s] may be made with accommodations), that the Decision-Maker was informed of what they were signing and that they were doing so voluntarily. For this reason, the witnesses (who, as with most other agreements, need to be nonparty adults) need to be aware of, and understand the Decision-Maker's chosen means of communication, although they may use supports/accommodations to do so. This is particularly relevant where the Decision-Maker does not communicate verbally.

Other formalities, such as notarization or additional qualifications (or disqualifications) for witnesses add little or nothing to the integrity of the execution, while potentially increasing the difficulty and discouraging parties from entering into SDMAs that would otherwise receive legislative recognition.

**XII. SDMAs should be the result of a process of facilitation or education designed to ensure that the Decision-Maker understands what goes into making a decision and obtaining support, and that Supporters understand their roles and how those roles may differ from their pre-existing relationships with the Decision-Maker**

When the legislature imposes an obligation on a third party to accept a decision made pursuant to an SDMA by a person with DD whose legal capacity is otherwise in question, and grants immunity from liability for good-faith reliance on that decision, it should have a reasonable level of confidence that the SDMA represents a process that the person with DD (the Decision-Maker) has utilized in making that decision *with the support specified in the SDMA*. This requires more than just signatures on a form. As the SDMNY pilot has shown, it is the work of well-thought-out facilitation, or education, of the parties over time that provides the necessary guarantee that a supported decision by a person with DD should be accepted without reference to disability and on the same basis as all others.

SDMNY's experience is virtually unequivocal that when Decision-Makers—of any age and any level of impairment—begin the facilitation process, they lack critical knowledge and understanding of how decisions are made and often have little or no conception of themselves as decision-makers. They lack tools to take the decision-making process apart to determine where they want and need support, and where they do not, or how this may vary across the domains in which they may make decisions currently or in the future. They may need the assistance of the facilitator to identify appropriate persons to support them in making their own decisions, rather than continuing to have others make the decisions for them. They may lack—and need to be assisted in developing—the intrinsic motivation necessary to make their own decisions, including accepting the consequences of those decisions. Moving from a place of acquiescence to one of self-determination requires intrinsic motivation, and takes work and support.

Similarly, simply signing a “form” SDMA -does not mean that a Supporter, especially a parent, will easily or consistently throw off the familiar, paternalistic (and entirely understandable) role of “decider” and protector who “knows best” and, instead, recognize the Decision-Maker as an adult capable of making their own decisions with support. A substantial body of empirical research from Australia,<sup>10</sup> confirmed by SDMNY's experience, shows that “capacity building” is necessary to enable the trusted persons chosen by the Decision-Maker to authentically provide support for the Decision-Maker's own decisions over time. Like developing decision-making skills and intrinsic motivation for the Decision-Maker, capacity-building for Supporters takes time and a well thought out process.

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<sup>10</sup> See, e.g., Jacinta Douglas & Christine Bigby, *Development of an Evidence-Based Practice to Guide Decision-making Support for People with Cognitive Impairment Due to Acquired Brain Injury or Developmental Disability*, 42 *DISABILITY & REHABILITATION* 434 (2018), Christine Bigby et. al., *Delivering Decision-Making Support to People with Cognitive Disability: What Has Been Learned from Pilot Projects in Australia, 2010-2015*; 52 *AUS. J. OF SOC. ISSUES* 224 (2017)

Because a Decision-Maker can remove, replace, or add supporters at any time, and repeating the full facilitation process for new supporters is, at best, impractical, there should be provision for more time and financially efficient means to educate new supporters of their role and responsibility. To the extent that a governmental entity such as OPWDD is responsible for, or oversees the facilitation/education process envisioned in this Principle, it should make available effective learning tools such as a Guide for Supporters and/or web-based information on how to provide support in accordance with the SDMA and the Decision Maker's right to make their own decisions.

Virtually every intentional SDM pilot project around the world and in the US has utilized a facilitation process for making SDMAs with its Decision-Makers and their Supporters, and for good reason. While SDMNY's three-phase facilitation process may not be the only way to ensure the integrity of an SDMA, it seems clear that *some* meaningful process is necessary.

Yet none of the SDMA laws passed in the US to date have required anything other than signatures on an approved form or agreement with prescribed terms, executed with formalities, and they require nothing about the process, if any, by which the SDMA was reached.

This provides an opportunity for New York to take a leadership role in promoting SDM as an alternative to guardianship in a way that ensures its integrity and promotes the self-determination and autonomy of people with DD. New York has invested substantial resources in determining how SDM can work as an alternative to guardianship for the diversity of its citizens with DD. This thoughtful, prescient effort should not be ignored as the legislature moves toward SDMA legislation for that population. It is significant that in the two jurisdictions where legislation has been motivated by a well thought-out, intentional pilot project, the resulting SDMA laws (currently pending in Massachusetts; enacted in Israel in 2017) include an educational requirement in order for legal recognition of decisions made pursuant to SDMAs.

***If an SDMA made by an adult with DD (the Decision-Maker) meets all the statutory requirements described in the above Principles, then***

**XIII. A person (third party) should be obligated to accept the legal capacity of the person with DD (the Decision-Maker) and give full legal effect to their decisions made pursuant to that SDMA, unless the third party has reasonable cause to believe that the decision is the product of exploitation or abuse**

One of the primary purposes—and benefits—of an SDMA law is that it explicitly confers legal recognition of decisions made pursuant to an SDMA that complies with the statute (a “recognized SDMA”). When a Decision-Maker makes a decision involving a legal transaction—to open a bank account, to have a particular dental procedure, to rent an apartment—the third party involved, whether banker, dentist or landlord, cannot make their own determination as to the Decision-Maker's legal capacity to enter into the transaction; compliance with the

recognized SDMA does that work, even as a properly executed statutory Power of Attorney removes the need for a third party to determine whether the person holding the Power is truly the agent of the principal.

It is important to note, however, that, since SDMAs provide that the Decision-Maker is not required to utilize the support(s) set out in the SDMA to make a decision, legislative recognition and the accompanying third party obligation is dependent on the decision at hand having been made *in accordance with the terms* of the recognized SDMA. A third party can obtain assurance of this by requesting an attestation by the Decision-Maker on a standardized form in accordance with **Principle X**.

In addition to removing uncertainty about the validity of transactions based on the consent or assent of Decision-Makers on the basis of their disability, and uncertainty that may be discriminatory and based on prejudice and stigma, an SDMA law demands, and ensures, that Decision-Makers are treated like everyone else. The result has many benefits: to the individual Decision-Maker, whose autonomy and dignity as a person are affirmed; certainty for the individual with whom s/he is entering a transaction; and, over time, a salutary change in the way in which people with disabilities are perceived by society as a whole.

The single exception to the third party's required acceptance of a decision made pursuant to a recognized SDMA—reasonable belief that the Decision-Maker is being abused or exploited in making the decision at hand—is intended as the built-in monitoring/protective aspect of an SDMA statute. The standard for declining to enter into the transaction, reasonable belief," means that it must be based on something more than prejudice against people with disabilities or lack of belief in their decision-making capabilities. At the same time, it means that abuse or exploitation can potentially be caught at the point where it occurs or has legal consequence. This is a significant improvement over various kinds of "monitoring" systems, including court monitoring of guardianships, that may, or may not, uncover abuse or exploitation long after the fact.

Many people who seek guardianship for their loved ones, most usually parents, do so because of the belief that guardianship will somehow "protect" them. While there is good reason to believe that an engaged network of Supporters is more likely to see and take measures to stop abuse, neglect, exploitation and/or undue influence than the mere existence of a guardianship order, parents often believe that the judicial imprimatur means that there is ongoing court involvement. It must be noted that, at present, SCPA 17-A has NO reporting requirement for personal needs guardians, minimal reporting requirements (all too often honored in the breach) for property guardians, and NO provisions at all for review.

The first, pre-SDMA, "SDM" law, British Columbia's Representation Agreement Act, provided for "monitors," and imposed certain duties and obligations on those monitors and third parties with whom Decision-Makers entered into transactions. There is little evidence as to how, or even whether, this embedded monitoring system has been effective, and no current SDMA

statutes include provisions for monitors. Any legislatively required or sanctioned monitoring would necessarily involve a whole additional layer of regulation, with no certainty of any benefit. Instead, the protection from reporting in XV, below, is intended to serve as a point-of-decision protective device to catch, and hopefully prevent, abuse or exploitation as it is being attempted.

**XIV. A person (third party) who, in good faith, relies on a decision made pursuant to that SDMA should not be subject to civil or criminal liability, or to discipline for unprofessional conduct**

In return for required acceptance of a Decision-Maker's decision, it is both appropriate and necessary for the legislature to confer immunity for the third party's good-faith reliance on the SDMA. The legislature has essentially said that compliance with a recognized SDMA stands in for legal capacity, even as a Power of Attorney stands in for proof of agency on which third parties can rely, and for which they are also relieved of liability.

Every SDMA statute requiring acceptance of decisions made pursuant to the SDMA includes immunity from civil and criminal liability for good-faith reliance. Most statutes also provide that, in the case of regulated and/or licensed professions, it also precludes disciplinary action and such protection is critical to ensuring that Decision-Makers with recognized SDMAs can secure professional services such as health care and legal advice and representation on an equal basis with all others.

**XV. A person (third party) who receives a copy of an SDMA and reasonably believes that the adult with DD (the Decision-Maker) is being abused or exploited should be protected if they report the alleged abuse or exploitation to the appropriate protective agency**

As discussed above, the reporting requirement on third parties, where there is a "reasonable belief" in exploitation or abuse, appears in most SDMA statutes, with only the appropriate protective agency for the jurisdiction (here, either Adult Protective Services [APS] or the Justice Center for People with Disabilities) a variable. It should be noted, however, that SDMA usage has not been correlated with increased risk of exploitation or abuse of the Decision-Maker; to the contrary, SDMA users and practitioners believe that SDMAs, including the "many eyes" of Supporters, add to the various protective apparatuses already in place to ensure the Decision-Maker's personal safety and financial well-being. And, while a third party who makes a report in good faith should suffer no undue consequences, the many cogent arguments against unnecessarily extending mandatory reporter status compel a similar conclusion where decisions made pursuant to a recognized SDMA are involved.