NEW YORK STATE | Office for People With Developmental Disabilities

OPWDD ASSESSMENT OF PUBLIC COMMENT

ADOPTED REGULATIONS

Supported Decision-Making

Comment: Several commenters suggested that language be added to the regulation to require care managers to discuss the availability of supported decision-making (SDM) with legal guardians and those subject to guardianship, to ensure they are aware of SDM as a supplement or alternative to legal guardianship. Additionally, some of these commenters suggested that if a legal guardian or person under guardianship is interested in SDM, the care manager should provide those parties with information regarding the modification or termination of the guardianship.

Response: Care managers and Care Coordination Organizations (CCO) are already required to assist members/enrollees and their circles of support with obtaining information about the availability of SDM as a supplement or alternative to guardianship. OPWDD agrees that this should include those currently under guardianship and their guardians. To this end, additional clarifying language was added to 14 NYCRR 634.10(a)(1)(iii) and (3) to better explain a CCO's responsibilities in this regard. However, it would be outside the scope of a care manager's responsibilities to provide legal advice related to modification or termination of a guardianship, so no additional change was made to the regulation to address the second portion of this comment.

Comment: Some commenters requested that language be added to the regulation to ensure that the notifications regarding allegations of abuse or neglect that are provided to persons receiving services be provided in an accessible format, and that a meeting with the service recipient be offered to review the notification, if necessary.

Response: While OPWDD agrees with the underlying premise of this comment, this requirement is already implied by broader principles of accessibility and access. Nonetheless, to ensure better clarity in the regulation, additional language was added to 14 NYCRR 624.5(a)(3)(i) that the information provided must be provided in an accessible format, upon request. No additional language is necessary to ensure the opportunity for a meeting to review, as a person receiving services already has the right to discuss any official notifications or similar materials by making a request to their care manager, the relevant agency, or the Developmental Disabilities Regional Office (DDRO).

Comment: Some commenters asked that additional language be added to the regulation to more closely examine potential conflicts of interest among members of the treatment team in their role to determine capacity related to informed consent for behavior service plans that include restrictive interventions under 14 NYCRR 633.16, and to introduce clarifying language in the regulation explaining how a person can

challenge a determination of lack of capacity under that regulation.

Response: OPWDD considered this comment, and no changes to the text of the regulation have been made. This rulemaking effort relates specifically to the implementation of Article 82 of the Mental Hygiene Law, and in doing so has included amendments to certain existing regulations that call for determinations of a person's capacity to make decisions for themselves. While amendments were made to ensure due consideration of supported decision-making agreements (SDMA) in the context of 14 NYCRR 633.16, it would be outside of the scope of this rulemaking to amend the existing process of determining capacity under that regulation where a person does not have an SDMA or otherwise make use of SDM.

Comment: Some commenters requested that OPWDD create a website to allow in the future for comments on proposed regulations to be submitted directly through a webform.

Response: This comment was considered, and the text of the regulation will not be changed. While not specifically a comment on the regulation proposed, OPWDD supports the idea of a web portal for submitting regulatory comments and will explore its viability for future regulatory proposals.

Comment: One commenter recommended the development of a list of authorized SDM facilitators to better allow those interested in SDM to identify and connect with active facilitators.

Response: This comment was considered, and the text of the regulation will not be changed. The development of a list of trained facilitators is already used by the SDM pilot program, and will, upon adoption of these regulations, be used by OPWDD in its review of applications by prospective facilitators for authorization. When necessary, the list of authorized facilitators will be made available to care managers for the appropriate referral of interested individuals. Until then, the SDM pilot program (Supported Decision-Making New York, www.sdmny.org) is prepared to make referrals for facilitation services.

Comment: Some commenters requested that an SDMA and any associated documents or information be prepared in an accessible format, in addition to its formal form.

Response: OPWDD agrees. This request is likely already required in existing regulatory language, and overarching principles of accessibility and access, but additional clarifying language was added to 14 NYCRR 624.5(a)(3)(i), 634.6(a)(1)(i), and 634.8(a), responsive to this request.

Comment: One commenter asked OPWDD to adopt the regulations as written and noted that supported decision-making could be life changing, but only if legally recognized and enforceable in court.

Response: OPWDD appreciates the enthusiasm and support for the promulgation of these regulations. Legal recognition of SDMAs is of paramount importance to ensuring the rights of people with intellectual and developmental disabilities are respected. It is encouraging to hear and that those who wish to make decisions for themselves are eager for the opportunity that SDM may afford.

Comment: One commenter endorsed the adoption of this regulation, but was concerned that decisions made in accordance with SDMAs may still not be legally recognized and enforceable.

Response: Ninety days following the adoption of this regulation, Article 82 of the Mental Hygiene Law will become fully effective. Once that occurs, formal SDMAs will be legally recognized and enforceable.

Comment: One comment explained that there is often an assumption that guardianship is necessary when a person reaches the age of eighteen. The commenter suggested that the education about SDM is needed for parents, caregivers, and others when someone nears the age of majority, regardless of someone's perceived decision-making capacity.

Response: This comment was considered, and the text of the regulation will not be changed. OPWDD agrees that education around guardianship and its alternatives is called for, especially for transition-aged youth. While outside the scope of this regulation, OPWDD will continue to promote and support efforts to educate students, families, and caretakers on the array of decision-making supports available to assist people with intellectual and developmental disabilities as they near the end of their education and transition into adulthood.

Comment: One commenter warned that some care managers are unaware of SDM, partly because standard forms used by CCOs and state agencies often ask for guardianship information but do not include a way to include information about supporters under an SDMA. This commenter described that when changing care managers, they have needed to explain to the new care manager what SDM is and justify the inclusion of supporters in planning meetings.

Response: OPWDD agrees that care managers and CCOs play a crucial role in ensuring that SDMAs are effectuated, and supporters should not be excluded from care planning (to the extent the SDMA so dictates). Though the proposed draft regulation already requires care managers and CCOs to become trained on SDM, additional language was added to 14 NYCRR 634.10(b) to clarify a CCO's record keeping responsibilities and ensure that all CCO staff responsible for coordinating services are made aware of the existence of an SDMA.

Comment: Some commenters called for additional education about SDM for physicians and other health care providers. Some commenters described difficulty in ensuring that supporters are allowed to participate in conversations with health care providers

because they are sometimes not considered legally authorized representatives.

Response: OPWDD agrees with the need for ongoing education for health care providers and others in the medical community. While outside the scope of OPWDD's regulatory authority to address, when Article 82 of the Mental Hygiene Law is effective (following the adoption of this regulation), health care providers will be bound by law to permit appropriately indicated supporters in a formal SDMA to participate in conversations regarding health care choices and treatment if the decision-maker under that SDMA so wishes and all appropriate releases have been executed.

Comment: One commenter suggested that despite the existence of Article 82 of the Mental Hygiene Law, without clear directives and announcements from state agencies, many third parties will not consider SDM legally binding. This commenter requested that OPWDD issue laminated cards to be issued to decision-makers and supporters under formal SDMAs and issue an official announcement to all providers of Medicaid services, as well as an informational webpage on OPWDD's website.

Response: While not directly a comment on the instant regulation, OPWDD will consider how to address the concerns in this comment. Upon adoption of the regulation, OPWDD will make a formal announcement, and additional administrative guidance will be forthcoming. OPWDD will continue to explore other avenues for community and professional education of relevant third parties.

Comment: One commenter described their desire to make decisions for themselves with the support of their loved ones if they ask for it. They explained that they do not want to be subject to guardianship because they see it as limiting their independence and preventing them from achieving their goals. They described wanting to maintain their autonomy with the option to get assistance if and when they ask for it.

Response: OPWDD appreciates the commenters support. This comment is illustrative of the position of many self-advocates OPWDD has heard from, and it is the agency's firm position that SDM—particularly as a formal SDMA—has immense potential to enable many people to maintain their autonomy, ensure their right and freedom of choice is respected, and promote the kinds of positive relationships that can best support them in making sound and thoughtful decisions reflective of their wishes, goals, desires, and preferences.

Comment: One commenter endorsed the regulation as written, explaining that it represents a significant step forward in empowering individuals with developmental disabilities to make their own choices and live more independently. They further explained that SDM acknowledges the universally cherished human right of legal capacity—to make one's own decisions and have them recognized, and especially now as statutorily recognized, provides a humane and empowering alternative to guardianship arrangements under SCPA Article 17-a. They expressed gratitude for OPWDD's effort and attention to detail in providing a clear framework for SDM's statewide implementation to ensure consistency and accountability in the support

provided to individuals with developmental disabilities. Specifically, this commenter explained that the provisions of 14 NYCRR 634.4, 634.5, and 634.6 provide a clear framework for the facilitation of formal SDMAs and the education of supporters in the SDM process.

Response: OPWDD appreciates this endorsement and will continue to strive to ensure Article 82 of the Mental Hygiene Law is effectuated with these sentiments in mind.

Comment: One commenter described the importance of the portions of the regulation at 14 NYCC 634.7 that attempt to reduce the possibility of discrimination on the basis of perceived capacity or competence. They emphasized that capacity is not limited to a person's innate abilities but should expand as needed in the context of a person's relationships and intradependence. To this end, the commenter described their appreciation of the edits made to existing regulations in Title 14 of the NYCRR, especially in areas surrounding consent, capacity, notice, and clinical protocols. The commenter explained that people with disabilities deserve the opportunity to exercise their rights with appropriate support as needed and declared in the United Nations Convention on the Rights of People with Disabilities.

Response: OPWDD agrees with the sentiment in this comment and appreciates the endorsement of the regulation.

Comment: Several commenters expressed support for the portions of the regulation (particularly those contained at 14 NYCRR 634.10) that describe the role of care managers and CCOs in the SDM process. One commenter explained that these clarifications are a critical component to ensuring the ongoing viability and relevance of individuals' SDMAs. Specifically, this commenter explained that the requirement that care managers advise on the availability of SDM and provide relevant information and materials will create a universal touchpoint for participation in SDM, allowing many more people to enjoy the rights afforded by Article 82.

Response: OPWDD appreciates this endorsement and agrees that the provisions at 14 NYCRR 634.10 will provide necessary clarity regarding the role of care managers and CCOs in the SDM process to better create access to SDM and facilitation services. Additionally, OPWDD agrees that the care manager and CCOs' roles are critical to ensuring the ongoing efficacy and viability of the SDMA as an instrument to allow for long-term decision-making support.

Comment: Some commentors expressed agreement with the provisions at 14 NYCRR 634.10, but concerns that no explicit language was included to require a care manager to investigate the continued viability of the SDMA after it is executed. They recommended additional language be added to require that an annual review of formal SDMAs be performed by the care manager to confirm that the SDMA is still meeting the needs of the individual, that the individual has the desired supporters identified in the agreement, that the supporters indicated are still available and willing to serve in the role of supporter, and that appropriate contact information is available.

Response: OPWDD has considered this comment and agrees that additional clarity surrounding the responsibilities of CCOs is appropriate. While periodic review of the SDMA was already required in the proposed regulation, this language has been updated to specify review should occur annually. And while some of the language in the proposed regulation, as well as the care manager's existing responsibilities, already imply the need for a care manager to verify the efficacy and viability of any decision-making support, including an SDMA, OPWDD agrees that additional clarity is helpful. Accordingly, additional language was added to 14 NYCRR 634.10 to reflect this commenter's suggestions.

Comment: One commenter expressed support for the regulations as written, noting that now that SDMAs will be legally recognized in New York, providing strong support and guidance for those involved will be essential to ensure that self-advocates can take advantage of the opportunity that SDM presents.

Response: OPWDD appreciates the endorsement of the regulation, and agrees that guidance for decision-makers, supporters, and third parties, including in the form of this regulation, the provisions of SDM facilitation, and the issuance of further administrative guidance materials will be essential to ensuring SDM's utility as a less restrictive alternative to guardianship.

Comment: One commenter requested that further amendments be made to 14 NYCRR 633.11 to clarify what is appropriate when a person with a formal SDMA that covers health care decisions is not able to consult with the designated supporter in response to or anticipation of proposed medical treatment. Specifically, the commenter requested additional clarification about when it is appropriate to look to one of the surrogates identified in 14 NYCRR 633.11 instead of the decision-maker under the SDMA.

Response: This comment was considered, and the text of the regulation will not be changed. While there may not always be time to consult with a supporter when faced with health care decision, the proposed additions to 14 NYCRR 633.11 already delineate the appropriate process when a formal SDMA is used in the context of medical decision-making. This includes primarily the expectation that a decision be made in accordance with the terms of the SDMA and the corresponding requirement that that health care practitioners honor decisions made in accordance with the formal SDMA. Additionally, 14 NYCRR 633.11(a)(1)(iii)(*h*) enumerates the circumstances when an exception to this corresponding requirement may be available to permit a health care practitioner to refuse to honor the decision made by the decision-maker. When such an exception applies, the surrogate structure available under that regulation remains available to secure consent for a health care decision.

Comment: In a comment similar to earlier comments related to the need for appropriate education about the existence and availability of SDM and facilitation services (among, e.g., potential decision-makers, their families, potential supporters, COO staff and care managers, oversight entities and their staff, OPWDD providers, clinicians, third parties,

and others), one commenter specifically requested that an eventual contractor for the continued provision of facilitation services (to be selected via RFP OPD-2024-39, released April 29, 2025) should be charged with this training responsibility.

Response: OPWDD agrees with the need for continued and expanded training on the existence and availability of SDM. While this comment is outside of the regulatory scope, and no associated change will be made to the text of the regulation, the aforementioned RFP does charge the eventual contractor with numerous training responsibilities, covering in scope many of the entities referred to in the comment.

Comment: One commenter expressed satisfaction with the proposed regulations, but requested that SDMAs should be able to cover support in the context of employment relationships, specifically so that a supporter can be present to participate in conversations with an employer of a decision-maker, in part to ensure that the decision-maker understands the content of those discussions and the expectations the employer has for the decision-maker/employee.

Response: This comment was considered, and the text of the regulation will not be changed. OPWDD agrees that employment is an important area for which decision-making support may be needed. Indeed, the regulation, and Article 82 of the Mental Hygiene Law, specifically reference support for employment-related decisions in their respective definitions of SDM. While no change will be made to the regulation in response to this comment, OPWDD would urge the commenter to explore the addition of employment-related decision-making support in their SDMA so that the desired supporters would have greater ability to participate in discussions with current and future employers.

Comment: One commenter noted concern that while 14 NYCRR 634.6(a)(1)(vii) confirms a decision-maker's right to change, amend or revoke an agreement for any reason, the regulations may appear not to prescribe a process for amending a facilitated agreement in order to ensure it remains in compliance with the requirements of Article 82 of the Mental Hygiene Law and the proposed regulations after amendment. The commenter provided the example that the regulations do not have a requirement that an amendment be facilitated or provide a remedy if a decision-maker is unable to locate the original facilitator to make a change to the agreement. The commenter noted further that they were unclear if an amended agreement that is not signed again by a facilitator following amendment is still considered a facilitated (formal) SDMA.

Response: This comment was considered, and the text of the regulation will not be changed. OPWDD acknowledges there may be instances when additional facilitation services may be needed after the execution of a formal SDMA. However, the provision of these additional services need not be explicitly referenced in the regulation, as nothing in the regulation as written currently precludes them. If requested by a decision-maker, facilitation services may be made available to accompany an amendment or other significant events, particularly in instances where new supporters are added to an agreement or where more substantial amendments to the SDMA may be required to

reflect changing roles among supporters. Consistent with the language of Article 82, an amended agreement remains valid without additional signature by a facilitator. Amendments to an agreement should always be accompanied by the original agreement with the original signature, so it remains clear that the SDMA was appropriately facilitated and executed in the first instance.

Comment: One commenter expressed concern that the presumption of capacity to enter into an SDMA as described in 14 NYCRR 634.7 does not extend to those with a legal guardian whose granted authority conflicts with the proposed supported decision-making agreement. Further, the commenter explained that because guardianships granted under SCPA Article 17-a are often plenary in nature, and proceedings under that statute do not necessarily include a capacity assessment of cognitive or adaptive functioning, it would be a violation of those individuals' rights to presume a lack of capacity to participate in SDM on the basis of the existence of a guardianship alone.

Response: OPWDD has considered this comment, and the text of the regulation will not be changed. Where a guardianship is plenary, it is indeed likely to conflict with any SDMA proposed under Article 82 and the instant regulation. This may well preclude many people subject to Article 17-a guardianships from executing a formal, or otherwise legally enforceable SDMA. The regulation does not extend the presumption of capacity to enter into an SDMA to those with guardianships that conflict with a proposed SDMA, but it also does not describe a presumption of *lack* of capacity to enter an SDMA on the basis of guardianship alone. A person under Article 17-a guardianship can still make use of informal SDM, or even request facilitation services to explore SDM and pursue an agreement that approximates a formal agreement. This may be possible with or without the participation of the guardian. There may also be instances where a period of successful use of an informal SDMA may have a bearing during guardianship modification or termination proceedings in demonstrating that a plenary (or other form of) guardianship is no longer needed or the person's best interest.

Comment: One commenter explained that SDM is often the primary evidence relied on by people under guardianship when they seek to terminate their guardianships. The commenter expressed concern that removing the less restrictive option of SDM from a person living under guardianship could result in further limiting an individual's right to challenge their Article 17-a guardianship, particularly where a guardian has died or opposes removal of the guardianship. They further noted that if SDM remains out of reach, those with non-responsive guardians would particularly lose an important means to achieve freedom and autonomy. The commenter posited that 14 NYCRR 634.7 as written removes the ability of a person to use an SDMA as evidence of the existence of a less restrictive means to prove Article 17-a guardianship is not necessary. This commenter suggested that the prohibition on people with disabilities under guardianship participating in SDM without the authorization of their guardian would be discriminatory under both Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act and would result in discrimination based on their disability. Finally, the commenter requested that because Article 17-a guardianships are based primarily on diagnosis, to ensure that people are not excluded from participation in supported

decision-making because of diagnosis, people living under guardianship should be permitted to participate in the facilitation process.

Response: OPWDD has considered this comment, and the text of the regulation will not be changed. As explained in the previous comment response, the regulation does not preclude or prohibit participation in SDM on the basis of the existence of a guardianship. Instead, it does not afford the presumption of capacity to enter into an SDMA to someone with a guardianship that is in conflict with a proposed SDMA. Additionally, where a guardianship is in conflict with a proposed SDMA, it does not require the authorization of a guardian to make use of informal SDM or preclude a request for facilitation to develop an SDMA that approximates a formal agreement. The regulation does not exclude from participation in SDM or SDM facilitation those with guardians—even those whose guardians who may not endorse a person's use of SDM—but the enforceable use of SDM by those with plenary guardianships may still be limited. It is consistent with Article 82 of the Mental Hygiene Law to ensure that where a guardianship and an SDMA (either formal or informal) are in conflict, the guardianship would supersede, which may thus present a limit on the potential enforceability of the SDMA. OPWDD encourages the use of SDM by those for whom it would be valuable in achieving greater autonomy and self-determination, including those with guardians. OPWDD acknowledges that SDM can serve as a valuable means for those under guardianship to become familiar with the challenges of decision-making and ultimately demonstrate that they are capable of making decisions about their lives for themselves. Indeed MHL 82.04(e) makes clear that the existence of an SDMA may be evidence that a person has a less restrictive alternative to guardianship in place, and the regulations do not restrict the possibility of developing an SDMA for this purpose. Nonetheless, it is outside of the scope of OPWDD's regulatory authority to further expound upon the Mental Hygiene Law's directive to courts.

Comment: One commenter explained that the wording of 14 NYCRR 634.5(a)(2)(i)(*b*) could leave room for confusion as to whether the supporter can make decisions to withhold or withdraw life sustaining treatment when permitted under SCPA 1750-b or PHL 29-cc. The commenter proposed alternate language to ensure greater clarity.

Response: This comment was considered, and the requested edits to 14 NYCRR 634.5(a)(2)(i)(*b*) were made to ensure clarity. The meaning of this clause remains unchanged.

Comment: One commenter explained that the language at 14 NYCRR 634.5(a)(2)(i)(*b*) and (*c*) may cause confusion if the supporter is not also a surrogate under the PHL 29-cc, SCPA 1750-b, or relevant OPWDD regulations. The commenter expressed that in such a situation, the supporter may still be considered a surrogate under MHL Article 80. They suggested that the authority for a supporter to act as surrogate under SCPA 1750-b or PHL 29-cc should instead by listed under a new subclause at (*c*)(*3*).

Response: This comment was considered, and the text will not be changed. OPWDD appreciates the commentor's intention to clarify that a supporter may be considered a

surrogate under MHL Article 80 if they were authorized as a surrogate under SCPA 1750-b or PHL Article 29-cc. However, 14 NYCRR 634.5(a)(2)(i)(*c*) refers only to surrogate status granted under existing OPWDD regulations (e.g., 14 NYCRR 633.11, 633.16, or other relevant regulations) and is not intended to capture all circumstances where surrogate or substitute status is currently conferred by law.

Comment: One commenter noted that the language in 14 NYCRR 634.5(g)(2) may create confusion for stakeholders trying to determine if they have mandated reporting requirements. The commenter proposed clarifying language to be added following the existing language in that paragraph.

Response: This comment was considered, and the requested edits to 14 NYCRR 634.5(g)(2) were made to ensure clarity. The meaning of this paragraph is unchanged.

Comment: One commenter noted that while the language of 14 NYCRR 634.7(a) mirrors Mental Hygiene Law 82.03(a), the Surrogate Decision-Making Committee (SDMC) process remains a viable option for individuals to receive informed consent for major medical treatment and end-of-life care. The commenter expressed concern that at times, clinicians may have established that an individual lacks capacity, which would grant them access to SDMC decision-making and an active consideration of their potential lack of capacity, but the presumption of capacity in the statute and this portion of the regulation could result in them being overlooked for declaration to an SDMC. The commenter proposed additional language to 14 NYCRR 634.7(a) to qualify that the presumption of capacity to enter into an SDMA would not extend to those who have "been evaluated and determined to lack the capacity to appoint a supporter." They noted the same considerations for the definition at 14 NYCRR 634.99(a) and proposed corresponding language be added to that paragraph.

Response: OPWDD has considered this comment, and the language of the regulation will not be changed. The proposed additional language would conflict with the basic framework of MHL Article 82, which does not only permit participation in SDM based on a clinical standard of capacity to enter into and SDMA or appoint a supporter. The law specifically presumes capacity to enter into an SDMA, which includes the appointment of supporters. Introducing in regulation the idea of a clinical evaluation to demonstrate capacity would defeat the Article 82 explicit presumption of capacity absent any of the enumerated exceptions. Furthermore, an SDMC's evaluation of capacity is based the statutory standard provided in MHL Article 80, which can still be applied where statutorily appropriate under the terms of the declaration made to SDMC. Within any evaluation of capacity during an SDMC proceeding, the committee will now also have the responsibility under MHL Article 82 to consider capacity within the context of the supports provided for in the SDMA.

Comment: One commenter wished to highlight that stakeholders should remain cognizant that individuals should retain an active role in the process for establishing the agreements contemplated by these proposed regulations. The commenter suggested language be added to 14 NYCRR 634.7(c) to state: "individuals in a formal supported

decision-making agreement shall not be subject to unilateral decision-making in which they lack participation in a shared
process through which the agreement is finalized."

Response: This comment was considered, and the language of the regulation will not be changed. OPWDD agrees with the premise that decision-makers under SDMAs should actively make their own decisions in accordance with their SDMAs. However, the suggested language is not necessary to ensure that decision-makers retain an active role in the process of establishing an SDMA or enforcing a decision made in accordance with an SDMA. Because SDM is not *shared* decision-making, but rather *supported* decision-making, it is always only the decision-maker themselves that is in control of the process to finalize an SDMA and permitted to make decisions in accordance with that SDMA. While supporters can make suggestions and help interpret and communicate circumstances and decisions made in response to those circumstances, a supporter is never in the decision-making role and is granted no authority under the regulation to make decisions on behalf of a decision-maker, including in the process of creating and finalizing the SDMA.

Comment: One commenter suggested that the definition of supported decision-making at 14 NYCRR 633.99(c) may present potential ambiguity in the scope of "health care" within its penultimate clause. The commenter suggested alternate language that would have the effect of excluding from the definition of health care major medical decisions made by the SDMC.

Response: This comment was considered, and the language of the regulation will not be changed. As noted in a previous response herein, it is OPWDD's position that committees convened under the terms of Article 80 of the Mental Hygiene Law are still subject to the considerations and limits created by Article 82 of the Mental Hygiene Law, specifically with respect to the limits placed on third parties in limiting the decision-making authority of a person with an applicable SDMA covering health care decisions, as well as the requirement that capacity to make decisions be viewed in the context of relevant supports and accommodations. It would be inconsistent with Article 82 and the proposed regulatory Part 634 to exempt an SDMC from these limits and considerations, or to exclude the applicability of an SDMA from circumstances where an SDMC may otherwise be relied upon.

Comment: One commenter noted that 14 NYCRR 633.11 relies upon the definition of "professional medical treatment" at 14 NYCRR 633.99(da). They suggested that to create consistency across applicable regulations and asked that OPWDD consider amending "professional" to "major"—the applicable term used in MHL Article 80 and associated regulations promulgated by the Justice Center for the Protection of People with Special Needs, so that stakeholders using the SDMC process can see consistent terminology.

Response: This comment was considered, and the language of the regulation will not be changed. This change would be outside the scope of this regulatory effort; however,

this request will be considered in the context of future updates to relevant OPWDD regulations. While OPWDD agrees that consistency in this area would be beneficial, currently the definition of “professional medical treatment” and “major medical treatment” are not identical, which has at times also created confusion among stakeholders. Any changes made to the definition of professional medical treatment would have far-reaching consequences for people with developmental disabilities, OPWDD, and its providers, and should only occur following robust input from the stakeholders affected.

Comment: One commenter suggested that 14 NYCRR 633.11(a)(1)(iii)(*a*)(*8*) should be amended consistent with the corresponding technical change made to 14 NYCRR 633.11(a)(1)(iii)(*b*)(*9*).

Response: This comment was considered, and the requested technical amendment was made to ensure consistency. The meaning of the newly amended subclause is unchanged.

Comment: One commenter noted the potential severity of altering an SDMA with solely having available redress in the court system. They suggested that, in the context of medical decision-making, SDMC may offer a speedier yet detailed consideration of the individual’s capacity and need for a committee to stand in the place of the individual to secure authority for a medical procedure to occur. By resorting only to the court system to override the authority for decision-making, the provision may create a heightened burden on stakeholders seeking more flexibility to account for changes in the individual’s life in the context of proposed major medical treatment. The commenter suggested a revision that would have the effect of allowing an SDMC to override the authority of a person to make major medical decisions for themselves in accordance with an applicable formal SDMA.

Response: OPWDD agrees that greater clarity about the use of the SDMC in the context of proposed medical treatment would be helpful. However, the revision proposed would not be consistent with MHL Article 82’s premise, nor the proposed regulatory part as a whole, so the suggested change will not be made. It would not be in keeping with Article 82 intent to prevent people with applicable formal SDMAs from enforcing those decisions, or for third parties—in this case, the members of an SDMC—to unilaterally override the authority of a person with a formal SDMA. Resolving the possible perception of conflict between Articles 80 and 82 of the MHL may require legislative action, but OPWDD is committed to continue to explore this question with its sibling agencies. If the question can be addressed through regulation alone, OPWDD will seek to do so in a future regulatory effort.

Comment: One commenter suggested that the regulation may benefit from additional detail on how to determine if an individual can make decisions with or without a supporter to assist them. They continued to note that as these regulations become the underlying landscape of SDM, there could be a bigger pool of supporters available, and if there is not a clear outline of what capacity means for decisions with supportive

assistance, there may be potential supporters who do not fully understand the risks and benefits behind a medical treatment and will take on substantive decisions for medical care.

Response: This comment was considered, and the language of the regulation will not be changed. OPWDD agrees that clarity around the appropriate role of a supporter is necessary for supporters to provide the assistance desired by the person with a developmental disability (the decision-maker). To this end, OPWDD is committed to the continued availability of SDM facilitation, a process that does not only involve the decision-maker, but also their potential supporters. Facilitation is the primary mechanism to ensure that supporters are educated about SDM and aware of the gravity of their roles—including as they support decision-makers in making medical decisions. That said, supporters are not meant to take on substantive decisions for medical care, indeed they are specifically precluded from doing so outside of the context of the applicable exceptions. After and outside the facilitation process, ongoing education and support for decision-makers and supporters will also become an important element to realize the promise of SDM as an effective alternative to more restrictive forms of decision-making support and substitution.

Comment: One commenter noted that it may be unclear how OPWDD staff would know when an evaluation is needed to determine capacity, or exactly how an evaluator of capacity is meant to consider support provided in an SDMA in the evaluation. The commenter suggested that while the proposed 14 NYCRR 634.7(e) allows for this process, it may benefit from additional context on how it would work. Further, the commenter highlighted the potential lack of clarity on how the remainder of the proposed regulations would interact with this provision. The “notwithstanding” language may mean that there is an existing mechanism to address people without capacity, but they may benefit from additional clarity, since stakeholders may find them to be indirect and confusing when contextualizing this section with the remainder of the rulemaking.

Response: OPWDD has considered this comment, and no change to the language of the regulation will be made. As alluded to in the comment, evaluations for capacity in the context of existing OPWDD regulatory processes within Title 14, Chapter XIV, already have mechanisms to determine applicability and the standard for capacity. The notwithstanding language at 14 NYCRR 634.7(e) clarifies that the existence of an applicable formal SDMA supersedes the regulatory processes in the chapter with respect to those processes that may identify or appoint a surrogate to make decisions on behalf of an individual receiving services.

Comment: One commenter wished to highlight that medical providers may not understand the
specific considerations for the population of intellectually or developmentally disabled individuals who are subject to the processes leading to SDMAs. They suggested that some medical providers may resist accepting consent from someone who they do not easily
identify as having capacity, especially if they need to consult a supporter to resolve

questions around capacity. The commenter stated their belief that a plan for advocacy and a space for the perspectives of the members of this population is paramount in navigating hesitance from some medical providers.

Response: OPWDD agrees with this comment and intends to continue its ongoing advocacy efforts to educate the public, including medical providers. As part of the aforementioned procurement for an ongoing provider and coordinator of SDM facilitation services (see RFP OPD-2024-39), OPWDD will provide resources for robust community education efforts, both directed at the broader public, and critical stakeholder groups, such as hospitals and medical providers.

Comment: Some commenters suggested that a procedure should be developed for determining the level of capacity needed for a potential decision-maker to be able to participate in the process of creating an agreement.

Response: OPWDD has considered this comment, and no change to the language of the regulation will be made. MHL Article 82 is clear that anyone without a legal determination of incapacity or a guardianship that conflicts with the proposed SDMA is presumed to have the capacity to explore SDM. However, while informal SDM continues to be available for all, if a person cannot actively and fully participate in SDM facilitation, the process for creating a formal SDMA cannot be completed.

Comment: One commenter suggested that there should be a procedure for redetermining capacity where someone's capacity changes in the time after a formal SDMA is executed.

Response: OPWDD has considered this comment, but no change to the language of the regulation will be made. The question of shifting levels of capacity is addressed in the regulation with respect to end-of-life decision-making under SCPA 1750-b (see proposed addition at 14 NYCRR 633.10(a)(7)(v)). For other circumstances where capacity may have shifted, or where concerns otherwise arise with respect to a decision-maker's ability to make appropriate use of their SDMA, concerned parties may seek guardianship or rely on the other exceptions to the authority of an SDMA available under MHL Article 82 (and corresponding regulatory provisions at e.g., 14 NYCRR 634.7(e), 634.8(b), and elsewhere).

Comment: One commenter requested that a glossary of terms should be added to Title 14, Chapter XIV, particularly to address the abbreviations used throughout the proposed Part 634.

Response: OPWDD has considered this comment, and no change to the language of the regulation will be made. No new abbreviations or initialisms are used in the proposed Part 634. A glossary relevant to Part 634 is proposed at section 633.99. Chapter XIV contains numerous other glossary sections within its respective Parts and Subparts.

Comment: One commenter noted that the role of the supporter is defined in the regulation at 14 NYCRR 634.5 in such a way as to limit undue pressure or duress on the decision maker, but also expressed concern about the possibility for a supporter to nonetheless exert undue or inappropriate pressure or influence on the decision-maker. The commenter suggested that a supporter's own biases may be difficult to overcome.

Response: This comment was considered, and no change to the language of the regulation will be made. OPWDD acknowledges that there remains the possibility and risk of the application of inappropriate pressure by supporters on decision-makers. However, MHL Article 82 contemplates that because supporters do not have decision-making authority over decision-makers, these risks are not substantially greater based on someone's status as a supporter (versus their natural roles as parent, family member, friend, etc.). Moreover, the regulation provides at 14 NYCRR 634.8(b) a variety of circumstances under which any concerned party may notify OPWDD or the Mental Hygiene Legal Service (MHLS) of their concerns. These include notification when a supporter is believed to have violated its duties and obligations under 14 NYCRR 634.16.

Comment: Some commenters expressed concern that the regulations at 14 NYCRR 634.5(a)(2)(i)(*b*) and (*c*) provide more detail about circumstances under which a supporter may be permitted to make decisions on behalf of a decision-maker than does MHL Article 82.

Response: These comments were considered, and no change to the language of the regulation will be made. The additional detail provided in the aforementioned clauses are based on reasonable holistic legal interpretation of MHL Article 82, and MHL 82.05 specifically, as well as a balancing of the interactions between MHL Article 82 and other relevant statutes, including, but not limited to, SCPA 1750-b and PHL Article 29-cc.

Comment: One commenter questioned why there is no process in the regulation to assess the effectiveness of a supporter over time.

Response: OPWDD has considered this comment, and no change to the language of the regulation will be made. MHL Article 82 does not call for a review or assessment of the effectiveness of a supporter and is framed to allow for the decision-maker to decide whose support and advice they wish to rely on. Instead, as mentioned in a previous response, the regulation makes available OPWDD and MHLS to make appropriate inquires where there exist concerns about the behavior or availability of a supporter or other involved party.

Comment: One commenter noted that the regulation identifies the process for agency providers of services to follow with respect to SDM facilitation. The commenter requested that similar rules be added for attorneys and other professionals who may look to offer fee-based SDM facilitation

Response: OPWDD has considered this comment, and no change to the language of

the regulation will be made. While OPWDD does not have regulatory authority over attorneys and other professionals with respect to their professional obligations, to the extent a professional is acting as a facilitator for someone who wishes to execute a formal SDMA, they would be required to become authorized by OPWDD to provide facilitation services and meet the facilitation guidelines and standards maintained by OPWDD.

Comment: Some commenters expressed that because informal SDM and SDMAs are available under the regulation, more clarity and guidance is needed for the enforceability and applicability of decisions made under these informal arrangements.

Response: The regulation makes repeated reference to due consideration that must be paid to decisions made through the use of informal SDM, but also clarifies that those decisions are not enforceable against third parties, as decisions made in accordance with formal SDMAs are. It is OPWDD's expectation that providers and other third parties will make good faith attempts to reconfigure their assessments of capacity to afford those using SDM informally additional consideration, and not assess them outside of the supports offered by those informal arrangements. While no changes will be made to the regulation in response to this comment, future administrative and clinical guidance will be issued to further discuss the informal use of SDM.

Comment: One commenter requested that references in existing regulations within Title 14, Chapter XIV to "medical service coordinators" be replaced and updated to reference "care coordinators/managers."

Response: OPWDD agrees that references to "Medicaid Service Coordinator" should be replaced throughout Chapter XIV with reference to care managers or Care Coordination Organizations, as applicable. However, it would be outside the scope of these amendments to address this consistently throughout the chapter. OPWDD will include these changes in a future regulatory improvement effort.

Comment: One commenter questioned why, if supporters are entitled under an applicable SDMA to receive copies of medical records or other documents, the regulation does not include the requirement that medical records be shared with the supporters.

Response: OPWDD has considered this comment, but no change to the language of the regulation will be made. Though some SDMAs may allow for a supporter or supporters to receive copies of medical records or other sensitive clinical information, for the purpose of assisting the decision-maker in making a related decision, the sharing of those records is still the decision-maker's choice on a case-by-case basis. In other words, sharing sensitive information still requires consultation with and the confirmation of the decision-maker, so a blanket regulatory requirement to share that information would be overreaching and inappropriate. Moreover, for protected health information, or clinical records protected under the Mental Hygiene Law, an appropriate additional release must still be signed by the decision-maker to allow for sharing with another

party, including a supporter.

Comment: Some commenters expressed concern that because 14 NYCRR 634.4(e) ensures that virtually no person may be prevented from working with a facilitator if they wish to do so, facilitators will not have any discretion to refuse to continue to facilitate the creation of an SDMA if they found that SDM was not a viable option for a given individual.

Response: 14 NYCRR Part 634 and MHL Article 82 both contemplate that anyone who wishes to should have the opportunity to participate in SDM facilitation. While the regulation will not be changed in response to this comment, it should be noted that OPWDD still expects and requires facilitators to ensure that anyone for whom they are facilitating is able to sincerely participate in and complete the facilitation process. If someone has not been able to fully participate in facilitation, the facilitator cannot sign that person's SDMA, thus ensuring that the SDMA is not considered formalized nor fully enforceable under the law.

Comment: One commenter suggested 14 NYCRR 634.4(e) may not appropriately clarify whether the existence of a guardianship order would preclude entry into an agreement, though later provisions in the regulation suggest this alone would not bar working with a facilitator or entering into an agreement.

Response: This comment was considered, and OPWDD agrees that this suggestion, while already implied at other points in the proposed regulation, merits further clarification. The requested changes to this paragraph were made to ensure clarity.

Comment: One commenter requested clarification of 14 NYCRR 634.5(a)(2)(i)(*c*) with respect to a supporter's ability to refuse a request made by a decision-maker if the supporter has substantial causse to believe that the decision or request will cause the decision-maker substantial and imminent physical or financial harm.

Response: This comment was considered, and no change to the text of the regulation will be made. The referenced clause refers to the ability of the party that would effectuate a decision made in accordance with a formal SDMA to refuse to do so. It does not specifically refer to a supporter's ability to refuse because the supporter's role is primarily to provide advice and support. However, to the extent a supporter may also be the party in the position to effectuate a decision, they would also have the ability to refuse on the basis provided. Conversely, if the supporter was not the party in such a position, they would still be free to advise the decision-maker of the possible consequences of their decision, including to attempt to dissuade the decision-maker from making a decision the supporter did not believe was appropriate.

Comment: One commenter suggested that the language provided in 14 NYCRR 634.5(a)(2)(iv) barring the supporter from obtaining without consent "personal information about the decision-maker that is acquired for a purpose other than assisting the decision-maker in making a decision authorized by a formal or informal supported

decision-making agreement" is too broad. The commenter proposed that this should be limited to protected, privileged, or confidential information. The commenter also suggested that the permitted purpose for obtaining the information should be expanded to include "effectuating a decision" and not merely making a decision.

Response: This comment was considered, and OPWDD agrees that this suggestion, while already implied at other points in the proposed regulation and MHL Article 82, merits further clarification. The requested edits were made to ensure greater clarity.

Comment: One commenter expressed that an exception should be added to the language of 14 NYCRR 634.5(a)(2)(v) to bar the supporter from obtaining or using the decision-maker's private financial information and other similarly confidential information without the express written consent of the decision-maker. This commenter suggested that an exception should allow a supporter to monitor the decision-maker's financial information to ascertain whether fraud is occurring and to obtain personal health information to confirm the decision-maker's well-being.

Response: This comment was considered, and no change to the regulation will be made. While OPWDD agrees that it can sometimes be important for a supporter to have access to pertinent information and records of a decision-maker to assist in preventing fraud, it would be outside of the scope of OPWDD's regulatory authority to create the requested exception, as it would contradict Article 82 of the Mental Hygiene Law to allow a supporter to access a decision-makers confidential records without the express consent of the decision-maker.

Comment: One commenter suggested that the language at 14 NYCRR 634.5(a)(2)(vi) barring a supporter from entering into any form of debtor-creditor relationship should allow for simple transactional borrowing and lending of money between family members or friends (such as a decision-maker asking a supporter to pick up something for them at the store), which could currently be read to run afoul of the current language.

Response: This comment was considered, and OPWDD agrees with this suggestion. It was not the intention of this clause to prevent informal lending of money between decision-makers and supporters for simple transactional purposes. To better clarify this intent, a minor edit was made to this clause consistent with the commenter's suggestion.

Comment: One commenter expressed concern about the requirement at 14 NYCRR 634.5(a)(2)(vii) that a decision-makers must participate and be present in circumstances where a supporter assists in communicating the decision-maker's decision to a third party. They suggested that this would prevent, for instance, a supporter from scheduling a medical appointment at the direction of the decision-maker, or making a purchase at the direction of the decision-maker.

Response: This comment was considered, and the text of the regulation will not be changed. OPWDD disagrees that the language of this subparagraph would prevent the

supporter from taking the actions described in the comment. In the given examples, the decision in question is not the scheduling itself of the medical appointment or the completion of the purchase, but rather the choice to schedule the appointment or make the purchase. In other words, as long as the decision-maker actively requests that the supporter schedule the appointment on their behalf because they have already decided that they want the appointment, then the supporter would not be acting outside the scope of their responsibilities. The purpose of this provision is to ensure that a supporter does not unilaterally act in circumstances where a decision-maker would be needed to make a decision. To follow the hypothetical circumstances provided, the scheduling of the appointment at the decision-maker's request would be permissible, but discussing treatment options at or following the appointment without the presence and participation of the decision-maker would be impermissible.

Comment: One commenter expressed concern about the language at 14 NYCRR 634.5(g)(4) providing that a supporter is not to be considered "a person available, willing, and able to assist the decision-maker responsibly." The commenter wondered if this language would be too limiting and exclude altogether any supporter who could be considered a responsible person.

Response: This comment was considered, and the text of the regulation will not be changed. The paragraph in question refers specifically to determinations of eligibility for adult protective services (APS). The language used is the statutory language found at section 473.1 of the Social Services Law, referring to what is colloquially known as an "available resource" for the purposes of APS. Additionally, the regulation is clear that a supporter may still be considered an available resource for APS eligibility determinations, but not "by virtue of their role as a supporter." If their preexisting role in a decision-maker's life (e.g., as a family member) would permit their consideration as an available resource, the regulation does not affect such consideration or determination by a local department of social services.

Comment: Referencing primarily the language at 14 NYCRR 634.7(a), some commenters requested additional clarity about the possibility of a guardian participating in a formal SDMA, and when a guardianship might preclude someone from entering into a formal SDMA. Specifically, one commenter wondered whether a plenary guardianship of the person would prevent the execution of a formal SDMA that covered only financial decisions; or conversely whether a guardianship of the property would prevent execution of a formal SDMA that specifically excluded financial or other property-related decisions.

Response: These comments have been considered, and the text of the regulation will not be changed. As mentioned in a previous response, the intent of 14 NYCRR 634.7(a) is to ensure that where the language of a guardianship order is in direct conflict with an SDMA, the authority of the guardian will supersede that of the decision-maker under an SDMA. This dynamic may play out in different ways depending on the circumstances. Under the examples provided, no conflict would appear to exist between the guardianship and the SDMA, and the two could coexist. If a guardianship only covers

one area of decision-making, a formal SDMA that does not also cover that area will be unaffected by the existence of the guardianship. Certainly, where a guardianship of the person exists under SCPA Article 17-a, an SDMA would be free to extend to financial or property-related decision-making; inversely, a guardianship of the property only under Article 17-a would permit execution of a formal SDMA that covered other non-property-related decisions. Similarly, because guardianships under MHL Article 81 can be tailored specifically around the needs of the person, a formal SDMA could coexist with a guardianship where it was designed to specifically to avoid the powers granted to the Article 81 guardian.

Comment: Some commenters noted that 14 NYCRR 634.7(e)(2) creates an exception to a decision-maker's authority to self-consent under a formal SDMA where "the decision-maker has a guardian under article 17-A of the Surrogate's Court Procedure Act or article 81 of the Mental Hygiene Law whose granted authority empowers them to make decisions related to the consent in question." Some of these commenters expressed concern that non-lawyers would not be able to parse guardianship orders to determine the scope of the guardian's authority, or to understand a tailored guardianship order, especially those that may contain nuances related to the authority to consent to only some forms of medical treatment.

Response: OPWDD agrees that analyzing the meaning of a guardianship order is not always straightforward, especially for those unfamiliar with this sort of legal document. Nevertheless, some examination and analysis of the scope of a guardian's authority will at times be needed to determine the appropriate scope and enforceability of an SDMA, including by non-lawyers. While the text of the regulation will not be changed, OPWDD will make efforts to address this question in future administrative guidance or supplemental materials issued related to SDM.

Comment: One commenter expressed concern that the notice requirements contained in 14 NYCRR 634.8(a) may be overbroad. They suggested that the term "information" should be limited to information "material to the decision-making" or otherwise restricted in scope. They further suggested that the definition of "decision-making" should be narrowed to those decisions involving issues of material significance.

Response: OPWDD has considered this comment, and the language of the regulation will not be changed. OPWDD agrees that not all information need be shared with supporters entitled to notice under an SDMA; however, the language of the regulation already narrows the scope of information to that which a decision-maker is entitled to pursuant to Title 14 of the NYCRR. Only certain notice, notifications, and information is required to be given to individuals pursuant to Title 14 rules. Correspondingly, supporters would only be entitled to receive that information.

Comment: One commenter requested that the glossary at 14 NYCRR 634.99 should include a definition for "decision." Alternatively, the commenter suggested that the definition of "supported decision-making" should be narrowed to only apply to "material decisions" about a person's life.

Response: This comment was considered, and the text of the regulation will not be changed. Narrowing the definition of "decision" as suggested would risk impermissibly preventing decision-makers from receiving support in making any decision they felt were important to them. The nature of decision-making is definitionally subjective, and SDMAs are intended to flexibly cover any decisions in a person's life they feel are important. Similarly, defining "supported decision-making" would inevitably narrow the possible scope of support available under an SDMA in a way inconsistent with Article 82 of the Mental Hygiene Law.

Comment: One commenter requested that the glossary at 14 NYCRR 634.99 be relocated and renumbered to 634.4, as the definitions in the glossary are used through Part 634.

Response: This comment was considered, and the text of the regulations will not be changed. The organization of Part 634 is consistent with that of other regulations promulgated by OPWDD. It is standard organizational practice in Title 14, Chapter XIV to include a glossary at section 99 of a given part.

Comment: One commenter requested more detail in the regulation about the function of a facilitator. The commenter wished to better understand what qualifications a facilitator must meet and to see more detail about the content and curricula of SDM facilitation.

Response: This comment was considered, and the text of the regulations will not be changed. The definition of facilitation at 633.99 describes the role of a facilitator, and 634.4 provides the basic qualifications for the provision of facilitation services. The content of and curricula of specific services are not generally described in regulation. However, future administrative guidance will elaborate on the standards for providing facilitation services, as well as the typical content covered during facilitation.

Comment: One commenter requested more information about what the OPWDD-approved facilitator training program referenced at 14 NYCRR 634.4 will entail.

Response: This comment was considered, and the text of the regulations will not be changed. Training for facilitation will for the near future continue to be provided by the SDM pilot program (Supported Decision-Making New York, www.sdmny.org) and its subcontractors, with oversight by OPWDD. The content of the training program has been developed in the course of the pilot program's decade-long study of SDMAs and how best to ensure their efficacy and viability. Future training programs will be reviewed and approved by OPWDD, consistent with the regulatory requirement, and will be expected to build upon the methodology developed during the SDM pilot program.

Comment: One commenter suggested that the definition of "decision-maker" at 14 NYCRR 633.99(a) may be inconsistent with the definition provided at MHL 82.02(d).

Response: This comment was considered, and the text of the regulation will not be changed. The definition of decision-maker in the regulations is consistent with the statute's intent. In addition to making available formal SDMAs, MHL Article 82 provides for the continued availability of informal SDM, about which the regulation provides further clarity and attempts to operationalize. Accordingly, it is appropriate to include in the regulatory definition of decision-maker the use of supported decision-making more generally, not only the use of supported decision-making agreements.

Comment: One commenter expressed concern that the capacity to enter into an SDMA is too low and will have unintended consequences. They suggested that because of this, there will be cases where a decision-maker is exploited by a supporter, and that the capacity standard will make it more difficult to undo potential damage caused, or pursue a supporter who has acted inappropriately.

Response: This comment was considered, and the text of the regulations will not be changed. OPWDD appreciates the delicate balance that must be struck between affording individuals the right to self-determination and protecting them from abuse, neglect, financial exploitation, and coercion. Article 82 of the Mental Hygiene Law provides a framework for people with intellectual and developmental disabilities to exercise their preexisting rights and makes explicit the presumption of capacity to explore SDM. It is important to note that the standard for executing an SDMA is more flexible than, for instance, executing a power of attorney or health care proxy, because unlike those instruments, an SDMA confers no decision-making authority in a supporter and thus bears comparatively lower risk for exploitation by a supporter. As mentioned in a previous response, there will always be some level of risk that those in trusted relationships may use that trust to act inappropriately. However, because no decision-making authority is afforded to a supporter under Article 82 or this regulation, the risk and consequences of a supporter misusing their position is likely no greater than it would be were they not a supporter and only acting in their existing natural role as a trusted friend or family member.

Comment: One commenter expressed concern that someone using SDM or relying on an SDMA may choose to leave a residential facility or other OPWDD-supported program under which they had been receiving services. The commenter requested that some sort of “safe harbor” provision be added to the regulation to evaluate the capacity of that person to understand the nature and consequences of such a decision.

Response: This comment was considered, and the text of the regulation will not be changed. While OPWDD appreciates the intention of this comment, it is important to note that all OPWDD services, including residential services, are voluntary. Residents of OPWDD-certified facilities are free to leave those facilities if they wish, even without reliance on the use of SDM. That said, OPWDD regulations at 14 NYCRR 633.12 already contain protections that could be considered "safe harbor" protections insofar as they allow various other parties, including MHLS and actively involved family members, to delay or question a discharge initiated by a provider agency or a resident themselves.

Comment: One commenter noted that under 14 NYCRR 634.4(c), the facilitator of an agreement executed before the effective date of MHL Article 82 should also be required to meet the requirements at 14 NYCRR 634.4(a) and (b).

Response: This comment was considered, and OPWDD agrees that this suggestion, while already implied, merits further clarification. The requested edits were made to 14 NYCRR 634.4(c)(1) and (2) for greater clarity.

Comment: One commenter questioned why the regulation does not include explicit criteria related to age or lack of legal impediments included in the requirements to serve as a facilitator when these sort of criteria exist to serve as a supporter.

Response: This comment was considered, and the text of the regulation will not be changed. Criteria for becoming a facilitator are described at 14 NYCRR 634.4 and include approval by OPWDD and compliance with any additional standards regarding the facilitation process, as set forth by OPWDD. As with all other service providers, OPWDD may apply additional guidelines to provider approval as may be appropriate to ensure the quality and consistency of facilitation services.

Comment: One commenter posited that portions of 14 NYCRR 634.5 were inconsistent with MHL 82.05 in that they do not require that a supporter participate in facilitation and/or education programs developed under OPWDD regulations in order to enter into a formal SDMA.

Response: This comment was considered, and no change to the text of the regulation will be made. 14 NYCRR 634.5(a)(1)(vi) already requires that supporters must participate in the facilitation process for a decision-maker to enter into a formal SDMA.

Comment: One commenter questioned why 14 NYCRR 634.5 does not reference decision-making authority granted to a guardian under MHL Article 81 or SCPA Article 17-a, if the supporter has also been appointed as guardian under those statutes.

Response: This comment was considered, and the text of 14 NYCRR 634.5(a)(2)(i)(*a*) was amended for clarity consistent with this suggestion.

Comment: One commenter expressed concern regarding the use of the term "substantiated findings" [of abuse, neglect, financial exploitation, or physical coercion] used in 14 NYCRR 634.5(e)(5). The commenter explained that local departments of social services do not make "substantiations" with regard to allegations of abuse, neglect, exploitation, or coercion. This commenter further noted that adult protective services maintains no central registry relative to its investigations, and worried that this paragraph (and the corresponding statutory provision) may lead to a false sense of security that individuals who wish to enter into SDMAs will be protected from appointing supporters statutorily ineligible to provide such support.

Response: While limited to an extent by the statutory language, OPWDD agrees there

is a need for further clarity with respect to eligibility on the basis of prior abuse, neglect, financial exploitation, or physical coercion. To this end, minor technical amendments were made to 14 NYCRR 634.5(e)(5) to address this concern and better clarify the legislative intent of Article 82. Additionally, it should be noted that MHL 82.08(b)(2) only limits eligibility where a proposed supporter has been found to have committed abuse, neglect, financial exploitation, or physical coercion against the decision-maker, not other individuals.

Comment: One commenter expressed concern that neither the statute nor regulation provide the decision-maker with authority to obtain information about circumstances that would disqualify a potential supporter under 14 NYCRR 634.5(e).

Response: This comment was considered, and the text of the regulation will not be changed. Because there is no single central register or database under which allegations and investigations of abuse, neglect, exploitation, or coercion are held, ex-ante verification of a supporter may at times be challenging. However, because the statue and regulations require that findings of abuse, neglect, financial exploitation, and physical coercion be against the decision-maker themselves to be disqualifying, there is a greater likelihood that the decision-maker will already be aware of those investigations and their ultimate findings.

Comment: One commenter questioned whether 14 NYCRR 634.5(f) permitted OPWDD employees to serve as supporters, including in situations where a decision being made involved the possible discharge of the decision-maker from an OPWDD-certified facility.

Response: This comment was considered, and the text of the regulation will not be changed. The regulation does not necessarily prohibit staff of OPWDD-certified or operated facilities from acting as supporters, but instead grants their employers with discretion regarding the appropriateness of those arrangements. Additionally, all supporters are subject to rules regarding conflicts of interest, which would already prevent them from advising a decision-maker on matters in which they had conflicts--as the included example may present.

Comment: One commenter suggested that 14 NYCRR 634.6 be retitled “formal supported decision-making agreements,” if it is meant to apply only to formal SDMAs. Further, the commenter expressed that there should be clarifying information regarding informal SDMAs contained in the regulation.

Response: This comment was considered, and the text of the regulation will not be changed. While it is true that most of 634.6 refers to formal SDMAs only, subdivision (b) contains important considerations related to the use of informal SDMAs and the differences in their effect compared to formal SDMAs. Reference to both informal and formal SDMA is made throughout Part 634 and the additional amendments to existing regulations, with respective differences in applicability.

Comment: One commenter expressed concern about the standard for executing an

SDMA contained at 14 NYCRR 634.7(b). They suggested that the standard therein is lower than the capacity standard used in many other important documents and life events, such as entering into a contract, marriage, creating a last will and testament, or giving informed consent to medical treatment. The commenter further suggested that this standard would reduce protections for decision-makers and potentially provide protections for supporters who would use an SDMA to take advantage of a decision-maker.

Response: This comment was considered, and the text of the regulation will not be changed. The regulatory standard for execution of an SDMA provided in 14 NYCRR 634.7(b) is consistent with MHL 82.03(f). As mentioned in earlier response, it is important to note that unlike other instruments for decision-making support, SDMAs do not confer upon a supporter any decision-making authority, and accordingly, the risk of exploitation by a supporter is comparatively lower than it is by surrogates. Additionally, SDM is based on the premise that capacity should not be viewed outside of the context of available supports and accommodations, of which an SDMA can be one. While SDM is not suitable for everyone, where someone is able to make use of decision-making support and can appoint a supporter, SDM can enable those who may otherwise be refused the opportunity to make a decision for themselves to do so with the support they need.

Comment: One commenter suggested that 14 NYCRR 634.7(c) may appear to change the decision-making standard of all decisions inconsistent with the laws governing those decisions, especially to the extent that those decisions may currently require that a person understand the nature and consequences of a decision to be permitted to make one. The commenter additionally questioned what a capacity assessment under this subdivision would entail.

Response: This comment was considered, and the text of the regulation will not be changed. 14 NYCRR 634.7(c) is consistent with MHL Article 82 and only relates to decisions "made in accordance with [a] supported decision-making agreement." It is meant to clarify that where an applicable SDMA exists, the rights preserved by that SDMA supersede other references in Title 14 of the NYCRR that may describe a process for clinically assessing the capacity of an individual. Though MHL Article 82 may demand further consideration of formal SDMAs in contexts outside of the scope of OPWDD regulation, this subdivision does not refer to or change the decision-making standard included in any statute—it refers only to the provisions of Title 14. Reference to capacity assessments within Title 14 reflects the numerous circumstances in the Title under which capacity assessments are currently prescribed.

Comment: One commenter questioned why the regulation’s glossary does not include a definition of “support.” They specifically questioned whether advocating that a decision-maker make a particular decision would be considered support.

Response: This comment was considered, and the text of the regulation will not be changed. Support can take any number of forms, depending on the preferences of a

decision-maker. Instead of attempting to incompletely capture the many forms that support may take in the regulations themselves, it is more practical to instead refer to the terms of a given SDMA. The agreement itself can capture not only who the decision-maker wants support from, but what kinds of support the decision-maker wishes to receive. In this way, the flexibility of the SDMA is prioritized over an overly prescriptive regulatory approach.

Comment: One commenter questioned that the capacity assessment described at 14 NYCRR 633.10(a)(7)(v) and suggested it should include assessing the patient's understanding of the nature and consequences of any proposed treatment, and the nature and consequences of refusing such treatment.

Response: This comment was considered, and the text of the regulation will not be changed. The purpose of the addition of 14 NYCRR 633.10(a)(7)(v) is to attempt to balance the statutory requirements of MHL Article 82 versus SCPA 1750-b. In doing so, the capacity standards and intent of both statutes are relevant. Under this paragraph, the decision-making authority maintained by an applicable SDMA under Article 82 would supersede the authority of a physician to make a determination of incapacity solely on the basis of a person's developmental disability unless it can be reasonably demonstrated that in the time since the SDMA was executed, the person's developmental disabilities have progressed of changed such that the person no longer has capacity to make the decision in question, even with the supports provided by the SDMA.

Comment: One commenter questioned why the glossary at 14 NYCRR 633.99, as amended by this rulemaking, continues the use of the anachronistic terms "conservator" and "committee" which were supplanted in 1992 with the enactment of MHL 81 and the term of "guardian." They suggested that while there may still be some leftover pre-Article 81, "conservators" and "committees," reference to MHL Article 81 guardians should be added to that section.

Response: This comment was considered, and reference to guardians appointed pursuant to the Mental Hygiene Law was added to 14 NYCRR 633.99(br).