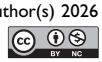
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Original research

Exploratory study of a supported decision-making intervention for adults with intellectual and developmental disabilities

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Abstract

Supported decision-making (SDM) is a legally recognized, person-centered approach that enables people with and without disabilities to make their own decisions with support from others. This study evaluated an 8-week virtual SDM pilot program for adults with intellectual and developmental disabilities using a pre-post design and introduced a facilitator guide adaptable to multiple settings. Pilot participants showed improvements in setting goals, making and expressing decisions, and seeking support when needed, along with overall gains across various SDM-related indicators. Findings suggest the intervention is feasible across diverse disabilities and support needs, with particularly strong benefits for individuals under guardianship. Future research should test the model with larger, more diverse samples and longer follow-up, as well as expand SDM training for providers, staff, and individuals to support broader model adoption.

Keywords

Community Living, Intellectual and Developmental Disabilities, Quality of Life, Self-Determination, Supported Decision-Making

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Introduction

Supported Decision-Making (SDM) is a person-centered decision-making paradigm that enables people with disabilities to make their own decisions with assistance from trusted supporters (Blanck, 2023; Blanck and Martinis, 2015; Shogren et al., 2018). In the United States, SDM has gained increased recognition in law, policy, and practice as an alternative to guardianship and other forms of substituted decision-making as well as a means of enhancing individual self-determination (e.g., Arstein-Kerslake et al., 2017; Blanck and Martinis, 2015). More than twenty U.S. states have enacted laws affirming or expanding access to SDM since 2012, reflecting a growing shift toward approaches that preserve individual autonomy and legal rights while ensuring access to needed support (Costanzo et al., 2022; Martinis et al., 2023; Whitlatch and Diller, 2022).

These developments in the United States align with international human rights standards articulated in the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Dinerstein, 2012). Article 12 of the CRPD states that people with disabilities have "legal capacity on an equal basis with others" and requires signatories to ensure that people with disabilities have access to supports they may need to exercise their legal capacity (United Nations Department of Economic and Social Affairs, 2006, art. 12). The CRPD Committee's General Comment No. 1 clarifies that Article 12 requires signatories to move away from substituted decision-making models such as legal guardianship and develop alternatives that respect the autonomy and preferences of people with disabilities (Committee on the Rights of Persons with Disabilities, 2014).

SDM occurs when individuals partner with chosen supporters such as family, friends, and professionals, who help them understand options, weigh alternatives, and communicate decisions. This process mirrors how most adults seek input from trusted others before making everyday choices, such as signing contracts, consenting to medical care, and managing finances (Blanck and Martinis, 2015; Peterson et al., 2021).

Studies document that people with intellectual and developmental disabilities (IDD) use SDM to make life decisions in ways that align with their abilities, needs, and preferences ((Browning et al., 2021; Harding and Taşcıoğlu, 2018), such as whether to engage in social and romantic relationships (Boni-Saenz, 2015; Harris, 2016; Series, 2015; Vehmas, 2019), to consent to and take part in medical and mental health care (Browning et al., 2014; Enck, 2021; Kokanović et al., 2018; Sapolsky, 2017), for legal representation (Gooding et al., 2021), and for capacity assessments (Jayes et al., 2022; Jayes et al., 2022). Using SDM enhances self-confidence, self-determination, and decision-making skills of individuals with IDD (Devi et al., 2020; Gunn et al., 1999; Shogren and Wehmeyer, 2015). SDM pilot programs find that people with cognitive impairments report that SDM improves their decision-making skills, increases their self-confidence and self-advocacy, and makes them feel more in control of their lives (Martinis and Beadnell, 2021; Then et al., 2023).

Existing studies and SDM pilot projects have largely documented, through descriptive or qualitative accounts, the kinds of decision-making support that individuals with IDD currently receive in practice (Dinerstein, 2012; Eyraud and Taran, 2023; Morichi et al., 2025). However, there is a general lack of structured interventions that operationalize SDM principles into a replicable program and formally evaluate whether such programs can be implemented and are associated with measurable improvements in decision-making (e.g., Morichi et al., 2025; Pillen et al., 2025; Sheerin et al., 2025).

The present pilot study helps to address this gap by designing, implementing, and assessing an eight-week SDM intervention for adults with IDD. Grounded in SDM principles, the program emphasized participant choice, flexible use of supporters, and individualized goal setting. We examined whether the intervention was associated with participant empowerment to understand,

make, and express decisions and to access support in ways that align with their abilities, needs, and preferences.

Background

SDM has gained recognition as an alternative to guardianship for people with IDD. Guardianship and other substituted decision-making arrangements transfer legal authority to another person, removing the right of individuals with IDD to make decisions in areas such as health care, finances, and relationships (Kohn, 2021). By contrast, SDM preserves the individual's active role as the primary decision-maker while acknowledging that support may be needed. In this framework, people with IDD choose supporters, such as family members, friends, or professionals, who can assist them in understanding information, considering alternatives, choosing between options, and communicating decisions without substitutes for their own final judgment (Salzman, 2011).

SDM reflects a broader societal recognition that decision-making is rarely an isolated act (Blanck, 2024). Most adults, regardless of disability status, rely on the perspectives of others before signing contracts, consenting to medical procedures, and managing financial matters. In this way, SDM mirrors everyday practices, formalizing them in ways that ensure respect for the rights and preferences of people with IDD (Peterson et al., 2021).

There is no single model of SDM. Supports may range from informal arrangements, such as asking a family member for advice about daily choices, to structured collaborations like micro-boards or circles of support that bring together multiple people to help the individual consider longer-term goals (Kohn et al., 2012). Across these variations, SDM arrangements share three core features: they affirm people's right to make their own decisions, they acknowledge that seeking or receiving support does not negate decision-making capacity, and they emphasize tailoring support to the individual's abilities, interests, and needs (Dinerstein, 2012).

SDM is tied to the concept of self-determination, understood as the ability to direct one's own life in accordance with personal goals and values. Research demonstrates that self-determination is a critical predictor of quality of life (Mumbardó-Adam et al., 2023). Through SDM, people with IDD can build decision-making skills, increase their confidence, and exercise greater autonomy. In turn, greater self-determination is linked to improved independence, better employment outcomes, and protection against risks such as abuse or exploitation (Hickson et al., 2015; Khemka, 2000; Khemka et al., 2005; Shogren et al., 2015).

SDM represents a practical paradigm and a rights-based framework for supporting autonomy among people with disabilities. By emphasizing individualized, evolving support, it offers a pathway for individuals to act as causal agents in their own lives while reducing reliance on restrictive legal interventions such as guardianship.

Purpose of the study

The purpose of this pilot study is to explore the feasibility and effectiveness of an eight-week SDM intervention program for adults with IDD with the functional capacity to participate in Zoom-based group sessions and respond to survey instruments administered verbally or through sign language. Using a pre-test/post-test design with a sample of 43 participants, this study examined the following overarching question: To what extent may an SDM-based intervention be associated with empowerment of people with IDD to understand, make, and implement decisions? To address this objective, we considered the following research questions:

1. How can an SDM-based intervention be implemented effectively for people with IDD with a range of support needs?
2. In what areas of life will participants tend to use SDM-based intervention to set goals?
3. In what ways are participants who receive an SDM-based intervention successful in making decisions, communicating their preferences and choices to others, and using support when needed?

Methodology

Participant recruitment for this eight-week SDM intervention program was conducted in partnership with two organizations, AHRC-NYC in New York City and Community Options in Pennsylvania, both of which offer long-term services and support to people with IDD, including residential programs, school-to-work initiatives, job training, and supported employment. The organizations' service provider staff met with eligible participants to describe and distribute fact sheets about the study and to answer any questions. Provider staff then offered technical support, when needed, for participants to connect via Zoom to individual questionnaire sessions and small group facilitation sessions.

The SDM-based intervention

We designed an exploratory intervention for this study grounded in the SDM principles outlined above and incorporating the following principles:

1. Each participant (an adult with IDD) is their own primary decision-maker;
2. Participants are invited to consider and decide on their interests, available choices, decisions, and goals;
3. Participants may decide who, when, and how many individuals they wish to consult regarding their interests, choices, decisions, and goals, including family members, friends, professionals (staff, teachers, doctors, experts), and neighbors;
4. Participants may change their minds at any time about their interests, choices, decisions, and goals; and,
5. Participants may change their minds at any time about whom they wish to consult regarding their interests, choices, decisions, and goals.

The SDM-based intervention uses a learner-centered approach that tailors facilitation methods to meet individual needs, interests, and learning styles. This approach fosters autonomy and positions individuals as co-creators and partners in the learning process (McCausland et al., 2022). Throughout the intervention, we considered the differential development of each individual across intellectual, emotional, and social domains and made accommodations for those differences and the participants' unique disabilities, backgrounds, interests, and experiences.

We refrained from taking an instructive or didactic approach to the intervention and instead developed an experiential approach whereby the participants practice making their own choices and obtaining needed support in planning and carrying them out. Participants were randomly assigned to a group made up of four other participants, and each group was provided with a facilitator. The groups met via Zoom once per week for one hour. We incorporated three anchoring activities to occur over the course of the eight weeks and to lead each participant to begin and experience SDM.

These activities were to be worked on during group sessions or completed as homework between sessions, depending on the needs of each group.

Supported decision-making facilitator guide

We developed the Supported Decision-Making Facilitator Guide for each facilitator to use as a roadmap for implementing the intervention. The Guide describes the subject matter, related discussions, and activities designed to enable participants to experience SDM in real time over the eight-week period. Once the intervention began, the facilitators met weekly with the project director to discuss group dynamics, participants' experiences and progress, creative modifications needed or developed to address participants' unique challenges, and any newly created approaches that proved helpful. The intervention aimed to create a supportive, enjoyable space for participants to share their ideas and interests and explore ways to turn them into action, rather than focus on teaching new information. Below is a summary of each group session's aims and activities.

First session. The goal of the first session was to set the overall tone for the intervention and help participants begin their journey toward SDM and greater self-determination. The facilitator began by encouraging participants to talk about what they like to do in their lives. As the discussion continued, participants were asked to think about activities they enjoy but had not done recently and then to think about activities they wanted to do for the first time. Toward the end of the session, the facilitator prompted participants to spend time before the next meeting creating a "Dream Board" with pictures or a list of things they would like to do in the future (e.g., Martinis and Gustin, 2017). The facilitator introduced this activity by sharing and explaining the development of their own Dream Board. These activities were meant to encourage participants to think about what they wanted in their immediate and long-term future and prompted them to consider, make, and communicate plans to achieve their goals.

Second session. The second session focused on having participants further develop and discuss their Dream Boards. Throughout this session, participants shared ideas about what they wanted to do, while the facilitator guided them to reflect more deeply, prioritize what mattered the most, rank ideas from easiest to hardest to achieve, and identify those that they were most excited about and why. This gave participants an opportunity to identify their goals and hopes for the future and consider ways to achieve them, including which goal to pursue first.

Third session. This session involved choosing goals and learning the importance of SDM. To start, the facilitator asked participants if they knew which goal they wanted to work toward over the remainder of the group sessions. The facilitator emphasized that participants may need support from family or friends to progress toward their goals and that receiving support is natural and something most people do frequently. Participants were asked to reflect on past support from a family member or friend and then seek advice from a trusted person on a current problem they were trying to solve. This introduced SDM as a means of making everyday and goal-oriented decisions by emphasizing support as a positive resource that enables individuals to achieve goals rather than something needed only when they cannot act independently.

Fourth session. The fourth session focused on the importance and creation of a support network. The facilitator asked participants if they had recently sought advice from a family member or friend to help them achieve the goal they identified in the prior session. Participants were prompted to create

a diagram, using the "Circle of Family and Friends" picture board (Pearpoint et al., 1992), showing their relationships with others they trust. These activities were designed to help participants engage in a fundamental part of SDM—identifying people they want to support them in making decisions in their lives. The facilitator stressed that the diagram was meant to be a living, evolving document, helping them identify existing and new supporters who can help them make decisions and achieve their goals.

Fifth session. This session focused on overcoming obstacles and realizing that new ideas can arise from setbacks or challenges. To start, the facilitator asked participants if they had sought advice from a family member or friend since the last session or asked for support with a problem they encountered while pursuing the goals they set in the third session. Participants were prompted to discuss problems they encountered, with the facilitator stressing that setbacks are a natural part of the process of achieving goals. The aim was to help participants understand the importance of adaptability in attaining goals and solving problems and to encourage them to modify, rather than abandon, their plans when they encountered obstacles to achieving them. For example, after participants reflected on times when they sought support from someone unwilling to help, the facilitator encouraged them to consider seeking alternatives in such situations.

At the end of the session, the facilitator asked participants to think about and discuss different ways that SDM had worked or may work for them, such as working with trusted supporters, having new or follow-up conversations, and using the internet to further explore options before making decisions. This helped participants reflect on their experiences using SDM and consider different ways to apply SDM in their lives.

Sixth session. This session focused on the importance of adjusting plans and processes as needed to progress toward individual goals. The facilitator asked participants if they had talked about their goals with potential supporters and prompted them to describe those conversations, including ways they sought support, outcomes, and obstacles they encountered. This was designed to encourage and empower participants to respond to challenges by adapting their plans and seeking the support they need.

Seventh session. This session focused on ways participants can change their plans when needed to help them progress toward their goals. The facilitator prompted participants to talk about times when they had changed plans to help them achieve a goal, the changes they made, and how they decided to make those changes. This was designed to show participants that making minor changes to their plans or support can help them reach their goals. In this session, participants were also asked to talk about how they were working with their supporters and whether their work together was affecting their lives outside the intervention. This gave participants a chance to provide real-time feedback on the sessions and empowered them to think about how they had sought, received, and used support in their lives.

Eighth session. In the final session, the facilitator and participants reflected on the intervention's broader focus. The facilitator began by fostering a discussion about how participants thought they were going to support themselves in the future and seek support to progress toward the individual goals they set in the third session. This was designed to empower participants to continue using SDM after the intervention ended, seeking and using support and adapting their plans as needed.

Participants were asked about their opinions of the intervention and how they felt about seeking support and using SDM in their lives. For example, the facilitator asked participants to share the

most important thing they had learned from the sessions and how it affected their lives. These reflections provided insights into the effectiveness of the intervention, as participants' ability to describe key lessons from the sessions suggested that they had internalized the SDM principles and processes while reinforcing the importance of seeking support not only to achieve the goal identified in the second session, but also in future decision-making situations.

SDM-based intervention implementation

Each facilitator met with one group weekly for an eight-week period. Based on discussions with participants and participating organizations, we determined that this duration would allow sufficient time to complete the core activities, including introductory discussions and follow-up conversations in which participants reflected on their experiences. In future applications of this intervention, the duration may vary depending on the needs of a particular group or participating organization.

Throughout this paper, the term "participants" refers to the 43 adults with IDD who enrolled in the SDM intervention; they are both the subjects of the research and the recipients of the intervention. The facilitators are members of the study team who delivered the intervention and contributed to the qualitative analysis through structured memoing and weekly meetings with the study director.

The study employed four facilitators, each assigned to lead one or more small groups. These facilitators were part-time researchers with doctoral-level training in clinical psychology or transitional health sciences. They were experienced in qualitative research methods and in facilitating support or therapy groups for a variety of populations, including those with IDD and psychiatric disabilities. They completed four one-hour Zoom sessions on the study's facilitation model and met weekly with the study director during the study to review the participants' experiences and progress, as well as ongoing dynamics and challenges in participant groups.

The 43 participants were randomly assigned to four-person facilitation groups that met once a week for eight one-hour sessions. Because this study began in 2020 during the COVID-19 pandemic, sessions took place remotely via Zoom. This proved advantageous, as remote sessions did not require participants to arrange weekly transportation. In addition, some participants required individualized accommodations over the course of the study (e.g., an American Sign Language (ASL) interpreter). Many of the participants had disabilities in addition to IDD, such as hearing impairments. Therefore, accommodations were provided as needed to ensure full participation in the intervention. Although the intervention was conducted via Zoom, it could also be delivered in person if circumstances allowed.

Each facilitator was given the Facilitator Guide that described the discussions and activities to be carried out during the eight sessions. The Guide noted that the discussions and activities were to be conducted in the order described, but their duration may vary depending on the needs of the participants.

Each participant completed a structured survey administered verbally by the facilitators via Zoom, before the intervention and after the eight-week sessions concluded. Each item was read aloud, and participants responded verbally or by indicating a number on a visual scale shared on screen. The survey took approximately 90 minutes to complete with pauses provided as needed to ensure accessibility. This study received Institutional Review Board (IRB) approval prior to recruitment.

Measuring study outcomes

As part of the study design, facilitators served as data collectors, by documenting participants' progress in setting goals, making decisions, and using supports through a structured memoing approach. After each session, facilitators wrote memos describing participants' goal-related support use, challenges encountered by participants, adaptations made by facilitators, and facilitator's reflections on session dynamics. These memos were shared with the study director and used as the primary data source for qualitative analysis.

Session memos served as a flexible, lasting record of the research journey, useful for personal reference or sharing with others (Birks et al., 2008). For facilitators, memoing served as an analytical strategy using participant-specific reports and as a way of connecting and communicating with other facilitators and the project director during their weekly meeting.

In these meetings and through memoing, facilitators described the implementation process and effectiveness of the intervention by evaluating its impact on participants' ability to use SDM to set goals and make decisions, using support when needed.

In addition to qualitative data, we collected outcome measures for each participant using 90-minute pre- and post-intervention surveys administered verbally by the facilitators. These included the Choice Questionnaire, a 26-item measure assessing how much control participants perceived over decisions in five life areas: domestic activities, money and spending, health, work and daily activities, and overall choice (Stancliffe and Parmenter, 1999). Respondents were asked to indicate whether they made decisions independently, with support, or if others decided for them. We also used the Supported Decision Making Inventory (SDMI), a 27-item self-reported tool assessing SDM among adults with disabilities across six subsections (feelings, experiences, opportunities, supports, decision-making, and decision implementation), using a five-point Likert scale from "very false" to "very true" (Shogren et al., 2017).

Additional variables considered included guardianship status (i.e., with or without a legal guardian), age, race, and ethnicity. Participants also indicated whether they had a disability, selected applicable types (e.g., intellectual, autism, hearing, vision, physical, mental health), and were invited to list any other conditions not captured. We recorded participants' educational attainment (ranging from less than high school to doctoral degree), employment status (part time, full time, unemployed, volunteer, sheltered, or vocational), and living arrangement (independent living, with family, group home, institution, or other).

We assessed the intervention along two dimensions. First, feasibility of implementation was defined as the ability of all participants to engage meaningfully in sessions; that is, to attend, participate in discussion, set at least one goal, and identify at least one supporter. This was evaluated through facilitator memos and weekly meetings between facilitators and the study director. Second, intervention-related outcomes were evaluated through qualitative analysis of session memos (examining goal progress, decision-making, and support use) and quantitative pre- and post-survey comparisons on SDM-related measures.

Analyses

For qualitative data, the study director conducted thematic analysis of the facilitators' notes and memos, an appropriate method for capturing patterns across qualitative datasets (Braun and Clarke, 2019). The themes derived established patterns of shared meaning organized around respondent outcomes and intervention implementation. For quantitative analysis, we conducted paired sample

t-tests using data from participants who responded to the baseline survey, participated in the full intervention, and responded to the follow-up survey (n=39).

Results

Sample description

The study sample consisted of 43 adults with IDD recruited from New York City, other parts of New York state, and Pennsylvania. Participants ranged in age from 18 to 69 years and represented a diverse mix of racial and ethnic backgrounds. The majority identified as Black (41%), Hispanic/Latino (34%), or White (25%), with smaller proportions identifying as Asian or American Indian/Alaska Native.

All participants had IDD, with many reporting additional conditions such as autism, mobility or sensory impairments, and mental health conditions. The sample consisted of individuals with relatively higher levels of adaptive functioning, as they were able to communicate verbally or through sign language and to participate in group discussions via Zoom.

Most participants lived either with family members or in group homes, and a smaller number lived independently. Employment status varied, including individuals who were unemployed, employed part time or full time, in internships or volunteer roles, or in sheltered employment settings. Nearly 40% of participants had legal guardians, while about 60% did not. A detailed breakdown of participant characteristics is presented in Table 1.

Feasibility and implementation of the SDM-based intervention

In evaluative meetings, facilitators and the study director found that participants were able to understand and apply SDM in the intervention sessions and their daily lives. All participants engaged in the group sessions by setting goals, identifying supporters, making decisions, and using support. The findings highlight the important role of facilitators in keeping discussions focused and helping participants refine overly ambitious goals into realistic short-term objectives, sometimes using visual aids such as spiderweb diagrams linking goals to actionable steps.

The base level of support delivered in the sessions enabled the majority of participants to meaningfully participate in the SDM-based intervention. However, two participants required more assistance from the facilitator, their peers, and their support system to meaningfully participate in the sessions and use SDM in their lives. For instance, one participant (James) initially struggled to remain focused during meetings and did not identify many personal goals. However, when a peer mentioned wanting to travel overseas, James drew on his personal knowledge of international travel to advise others on topics such as currency exchange, lodging, and scheduling. The facilitator's session memos noted that being recognized as knowledgeable visibly increased James's engagement and confidence for the remainder of the sessions.

Another facilitator noted that some participants had difficulties with the questions asked during the sessions. As an alternative, the facilitator created a PowerPoint presentation explaining Dream Boards, which helped participants better visualize the planning tool and the types of goals they might set.

In addition, this facilitator decided to share with participants the approach of setting specific, measurable, achievable, relevant, and time-bound ("SMART") goals to help them establish practical objectives. This approach, together with peer support, enabled all participants in this group to actively engage in the session. The facilitator introduced the SMART framework step by step,

Table 1. Sample description table.

Category	Attributes	Number	Percentage (%)
Participant overview	Total participants	43	
	Completed all surveys	39	91
	Gender - Men	28	65
	Gender - women	15	35
	Age range	18-69	
Race/ethnicity[a]	Black	18	42
	Hispanic/Latino	15	35
	White	11	26
	Asian	3	7
	American Indian/Alaska native	1	2
Disability types[b]	Autism	14	33
	Deafness	4	9
	Hearing impairment	2	5
	Vision impairment	3	7
	Mobility impairment	3	7
	Speech impairment	3	7
	Epilepsy/seizure disorder	1	2
	ADD	1	2
	Anxiety disorder	2	5
	Intermittent explosive disorder	1	2
Living situation[b]	With family	24	56
	Group home	12	28
	Independent	3	7
Employment status	Unemployed	18	42
	Part-time	11	26
	Internship	8	19
	Volunteer	4	9
	Full-time	1	2
	Sheltered employment	1	2
Guardianship status	No guardian	24	62
	Has guardian	15	38

Notes.
[a]Race is not mutually exclusive; participants could select more than one category, therefore percentages may exceed 100%.
[b]Not all participants completed every survey, resulting in some missing data; therefore, percentages may not total 100%.

provided examples for each component, and then had the group practice converting a non-SMART goal into a SMART one.

In discussions with the research team and facilitators, this group of participants underscored the importance of tailoring the intervention as necessary to meet their support needs. Even with the extra support offered by the facilitator, peers, and network of supporters, four participants in this group displayed different levels of engagement. Session memos indicated that most participants demonstrated strong understanding and motivation, eagerly applying concepts between sessions, while others had lower motivation or found it difficult to maintain attention during Zoom sessions.

Facilitators did not report significant challenges in implementing the SDM-based intervention for participants with relatively greater support needs. As noted, some participants required more assistance from the facilitator, their peers, and support systems to meaningfully participate in the

sessions and use SDM in their lives. Facilitators addressed these challenges by providing assistance and information in different modalities, and they emphasized to the research team the importance of customizing the intervention as necessary based on participant support needs.

Goal setting and outcomes: Qualitative findings

All participants in the pilot study were able to set and progress toward a range of goals. For example, several participants set goals around employment, and some of them took the first steps in achieving their goals. One participant decided to become a masseuse and started taking masseuse classes. Two participants wanted to obtain jobs, and by the end of the eight-week study they entered vocational rehabilitation job placement programs. One participant focused on finding a retail job that would involve customer service, ordering, checking inventory, and stocking shelves. Another participant wanted to manage a soccer team. When the group sessions began, he was working in a kitchen setting. After the eight-week intervention, he was transitioning to work with a recreational soccer league, improving his chances of moving toward a career in sports management. Another participant planned to seek a volunteer opportunity to help with church activities or to promote a political candidate.

A participant who was interning at a hospital decided to apply for a patient transport position. Another participant enjoyed painting houses. His long-term goal is to become a contractor for professional home remodels. To achieve that goal, however, he needed a driver's license. The group helped him focus on progressing toward his goal in a systematic way. This included practicing driving with his family members and studying for the exam. Two other participants also wanted to obtain driver's licenses. Although they did not accomplish this before the intervention ended, through the intervention, each developed a plan for the steps needed to achieve their goal.

Besides employment, participants set other diverse goals focused on improving their health, traveling, increasing their social media presence, and pursuing hobbies. One participant wanted to learn to ride a bike and accomplished it within eight weeks. Another participant developed a plan for traveling across the country to visit a friend. Two other participants each planned a beach vacation with their friends. The goal of another participant was to build up her online presence to support her interest in fashion, while another purchased a guitar and began teaching herself to play using online resources.

Study participants were able and more willing than they were before participating in this study to make life decisions using SDM. For example, Dylan identified the need to improve his social interactions and asked his peers for help. Through the sessions, Dylan and his peers decided how to pursue it and used the group as a network of supporters. Analysis of session memos indicated that as the weeks progressed, Dylan increasingly sought guidance from group participants regarding his social interactions. The group sessions became a psychologically safe space for him to discuss social challenges at his residence.

The intervention was also successful in providing participants with tools to identify supporters and request help from them when needed. When one participant was asked how she felt about the support she had been given by the people she chose for her friendship circle, she said, "I feel like they are there to help us break down things and they tell us step by step how to achieve them. They may not always be there, but they are our cheerleaders."

Another participant had a long-term goal of becoming a graphic designer for a comic book franchise to work on illustrations. During the facilitation group sessions, he identified several people, including his school librarian and an English teacher, who supported his goal by providing

guidance on authors and best-sellers within his genre of interest. He also sought out his guidance counselor for help finding internships and other opportunities in this area.

The long-term goal of another participant was to become a radio personality since he enjoyed all types of music. During the facilitation sessions, he identified the manager at his favorite music store as someone who may be able to give him guidance. This manager was well-connected to the local music scene, supporting local talent and organizing concerts. The participant also identified his music teacher as a helpful supporter and sounding board.

Some participants chose to use supporters who were paid staff with similar positive outcomes. For example, Troy initially expressed difficulty identifying people in his life who could support his fitness goals. Through group discussion and the topics covered in sessions, however, he identified several supporters and began coordinating with support staff to schedule his workouts. Session memos note that Troy openly shared his experiences with his circle of support and reflected positively on his progress during weekly sessions.

Similarly, Harold reported relying on paid staff as supporters and worked with them to set realistic goals, evaluate options, make choices, and seek support when needed. According to session memos, Harold made significant progress meeting with his program staff and advocating for saving money toward purchasing a new wrestling belt. At one point, he considered changing his goal but ultimately returned to his original objective. During sessions, he was able to identify the pros and cons of different spending choices and developed a plan to work with his group home manager to use available funds to meet his goal.

Positive outcomes associated with the SDM-based intervention: Quantitative findings

Quantitative findings are drawn from comparing participants' SDM-related scores before the intervention began with their scores after the intervention concluded, using pre-test/post-test design. The results indicate a positive association between the intervention and several of the SDMI items. Table 2 shows the progress for different subsections of the SDMI scores pre- and post-intervention.

We used t-tests to compare scores before and after the intervention and find that, on average, participants report feeling more supported making decisions and freer to talk about their ideas and opinions after the intervention than before it (see Table 2). In addition, we find that, on average, participants report a higher degree of support available to them to make decisions about their health and legal matters post-intervention. Similarly, on average, participants report needing a lower level of support to identify options and the possible consequences of their choices than before the intervention.

Not all SDMI items are positively associated with the intervention. Therefore, these preliminary findings should be interpreted with caution. In addition, given the exploratory and limited nature of this pilot study, we are unable to reach a conclusion about the magnitude and direction of the association between those items and the intervention.

We explored whether the association between the intervention and SDMI scores differed for participants under guardianship and those without. As shown in Table 3, improvements in SDMI scores tend to be stronger for participants under guardianship than among those without guardians. Most of the statistically significant results were not observed for those without guardians. This pattern may reflect greater opportunity for change among participants who previously had fewer opportunities to practice independent decision-making. These findings should be interpreted cautiously, however, as they are based on subgroup analyses of an already small sample.

Table 2. T-test results comparing overall SDMI scores and for 27 items pre-post intervention.

	Mean T1	Mean T2	p-value
SDMI feelings score	4.410	4.513	0.23
Q1. People in my life care about me.	4.795	4.923	0.17
Q2. I generally feel free to talk about my ideas and opinions.	**4.325**	**4.622**	**0.03**
Q3. Most days I feel a sense of accomplishment from what I do.	4.216	4.271	0.76
Q4. I have been able to learn interesting new skills recently	4.325	4.135	0.41
SDMI experiences score	**4.094**	**4.363**	**0.09**
Q1. To what degree have you had chances to be involved in decisions?	3.921	4.237	0.19
Q2. To what degree do you feel that you have been supported to successfully make decisions in the past?	**4.385**	**4.692**	**0.09**
Q3. To what degree do you see yourself as a good decision maker?	4.079	4.158	0.73
SDMI opportunities score	3.577	3.618	0.82
Q1. To what degree are there opportunities available for you to make high risk and/or complicated decisions about your health?	3.821	3.718	0.74
Q2. To what degree are there opportunities available for you to make high risk and/or complicated decisions about legal matters?	2.514	2.372	0.64
Q3. To what degree are there opportunities available for you to make high risk and/or complicated decisions about financial matters?	3.641	4.026	0.19
Q4. To what degree are there opportunities available for you to make high risk and/or complicated decisions about social/friendship relationships?	3.923	3.949	0.91
Q5. To what degree are there opportunities available for you to make high risk and/or complicated decisions about independent or community living?	3.923	4.051	0.65
SDMI supports score	**4.282**	**4.569**	**0.04**
Q1. To what degree are there supports available to enable you to make high risk and/or complicated decisions about your health?	**4.359**	**4.795**	**0.02**
Q2. To what degree are there supports available to enable you to make high risk and/or complicated decisions about legal matters?	**4.085**	**4.715**	**0.01**
Q3. To what degree are there supports available to enable you to make high risk and/or complicated decisions about financial matters?	4.385	4.564	0.19
Q4. To what degree are there supports available to enable you to make high risk and/or complicated decisions about social/friendship relationship?	4.316	4.421	0.63
Q3. To what degree are there supports available to enable you to make high risk and/or complicated decisions about independent or community living?	4.333	4.410	0.74
SDMI decision making score	3.200	3.043	0.44
Q1. What level of support do you need to understand why a decision needs to be made?	3.106	3.026	0.77
Q2. What level of support do you need to know when a decision needs to be made?	3.131	3.158	0.92
Q3. What level of support do you need to know that decisions lead to achieving a goal?	3.359	3.308	0.85
Q4. What level of support do you need to identify options that you know about for your decisions?	3.077	2.667	0.17
Q5. What level of support do you need to identify options that you didn't know about for your decisions?	3.231	3.051	0.60
SDMI decision implementing score	3.200	3.043	0.44

(continued)

Table 2. (continued)

	Mean T1	Mean T2	p-value
Q1. What level of support do you need to determine if each option will lead to reaching your goal?	3.103	3.051	0.86
Q2. What level of support do you need to identify known consequences of each option?	3.256	2.949	0.25
Q3. What level of support do you need to identify known risks of each option?	3.103	3.026	0.78
Q4. What level of support do you need to identify known benefits of each option?	2.769	2.897	0.62
Q5. What level of support do you need to rank options by your preferences?	**2.769**	**2.205**	**0.10**
Q6. What level of support do you need to determine which option and consequence will best lead to reaching your goal?	3.410	3.385	0.91
Q7. What level of support do you need to choose one option to perform?	2.744	3.051	0.36

Notes. Subsections one through four in Table 2 are positively worded and progress is measured by increasing scores, whereas subsections five and six are negatively worded and progress is measured in decreasing scores. For exploratory purposes, results with a p-value of less than 0.1 are indicated in bold.

Finally, there is evidence that the intervention, which supported participants in making and acting on specific decisions, influenced perceived choice across several areas of daily life, as measured by the Choice Questionnaire. Table 4 presents paired-sample t-tests results with lower scores indicating improvement. After the intervention, participants were more likely to report independently deciding on matters such as bedtime, household tasks, and pet ownership, among other choices.

Discussion

This exploratory pilot study aims to contribute to the growing literature on SDM training by testing an SDM-based methodology through an eight-week intervention tailored to the population with higher-functioning IDD (e.g., Morichi et al., 2025). In doing so, we have created a Facilitator Guide that may be adapted to other studies, settings, and populations. Preliminary findings suggest that the intervention is feasible for adults with higher-functioning IDD; its implementation enabled participants in this sample to engage meaningfully across a range of abilities and support needs. In addition, the exploratory findings suggest that the intervention was successful, insofar as it was associated, albeit not causally, with participants' setting goals, making and expressing decisions, using support when needed, and improved scores across a series of SDM-related measures.

Four key findings emerged from the study:

1. The intervention supported participants' use of SDM to set goals during sessions and pursue them outside of sessions. For example, the participant who transitioned from working in a kitchen to working with a recreational soccer league in pursuit of a career in sports management illustrated how SDM may support meaningful life decisions. This is consistent with research indicating that people with IDD can effectively use SDM to consider, make, and communicate decisions across multiple areas of their day-to-day lives (Harding and Taşcıoğlu, 2018).
2. The intervention may have enabled participants to seek support and make decisions in multiple life domains. Post-intervention, participants were more likely to report making

Table 3. T-test results comparing SDMI scores for 27 items by guardianship status.

	Without guardian		With guardian	
	Mean T2-Mean T1	p-value	Mean T2-Mean T1	p-value
SDMI feelings score	0.000	1.00	**0.267**	**0.09**
Q1. People in my life care about me.	0.000	1.00	0.333	0.14
Q2. I generally feel free to talk about my ideas and opinions.	0.125	0.38	**0.615**	**0.03**
Q3. Most days I feel a sense of accomplishment from what I do.	0.250	0.27	−0.308	0.30
Q4. I have been able to learn interesting new skills recently.	−0.375	0.27	0.154	0.44
SDMI experiences score	0.042	0.82	**0.633**	**0.02**
Q1. To what degree have you had chances to be involved in decisions?	0.083	0.77	0.714	0.12
Q2. To what degree do you feel that you have been supported to successfully make decisions in the past?	0.125	0.59	**0.600**	**0.05**
Q3. To what degree do you see yourself as a good decision maker?	−0.083	0.79	0.357	0.29
SDMI opportunities score	−0.246	0.25	0.500	0.14
Q1. To what degree are there opportunities available for you to make high risk and/or complicated decisions about your health?	−**0.625**	**0.09**	0.733	0.18
Q2. To what degree are there opportunities available for you to make high risk and/or complicated decisions about legal matters?	−0.048	0.91	−0.286	0.54
Q3. To what degree are there opportunities available for you to make high risk and/or complicated decisions about financial matters?	−0.125	0.73	**1.200**	**0.09**
Q4. To what degree are there opportunities available for you to make high risk and/or complicated decisions about social/friendship relationship?	−0.167	0.51	0.333	0.43
Q5. To what degree are there opportunities available for you to make high risk and/or complicated decisions about independent or community living?	−0.125	0.75	−0.533	0.19
SDMI supports score	0.023	0.87	**0.710**	**0.01**
Q1. To what degree are there supports available to enable you to make high risk and/or complicated decisions about your health?	0.208	0.33	**0.800**	**0.01**
Q2. To what degree are there supports available to enable you to make high risk and/or complicated decisions about legal matters?	0.286	0.36	**1.143**	**0.00**
Q3. To what degree are there supports available to enable you to make high risk and/or complicated decisions about financial matters?	−0.083	0.58	**0.600**	**0.02**
Q4. To what degree are there supports available to enable you to make high risk and/or complicated decisions about social/friendship relationship?	−0.130	0.64	0.467	0.20

(continued)

Table 3. (continued)

	Without guardian		With guardian	
	Mean T2-Mean T1	p-value	Mean T2-Mean T1	p-value
Q3. To what degree are there supports available to enable you to make high risk and/or complicated decisions about independent or community living?	−0.208	0.35	0.533	0.29
SDMI decision making score	−0.154	0.57	−0.160	0.61
Q1. What level of support do you need to understand why a decision needs to be made?	0.000	1.00	−0.200	0.55
Q2. What level of support do you need to know when a decision needs to be made?	−0.261	0.43	0.467	0.29
Q3. What level of support do you need to know that decisions lead to achieving a goal?	0.125	0.74	−0.333	0.44
Q4. What level of support do you need to identify options that you know about for your decisions?	−0.167	0.66	**−0.800**	**0.10**
Q5. What level of support do you need to identify options that you didn't know about for your decisions?	−0.333	0.47	0.067	0.90
SDMI decision implementing score	−0.155	0.58	0.029	0.91
Q1. What level of support do you need to determine if each option will lead to reaching your goal?	−0.000	1.00	−0.133	0.74
Q2. What level of support do you need to identify known consequences of each option?	−0.542	0.13	0.067	0.88
Q3. What level of support do you need to identify known risks of each option?	−0.125	0.74	0.000	1.00
Q4. What level of support do you need to identify known benefits of each option?	0.083	0.81	0.200	0.61
Q5. What level of support do you need to rank options by your preferences?	−0.292	0.48	**−1.000**	**0.10**
Q6. What level of support do you need to determine which option and consequence will best lead to reaching your goal?	−0.208	0.53	0.267	0.43
Q7. What level of support do you need to choose one option to perform?	−0.000	1.00	0.800	0.11

Shown in bold are statistically significant results with a p-value < 0.1.

decisions about bedtimes, household activities, and pet ownership, while needing less support to identify options and consequences. This suggest that participants used decision-making support while simultaneously perceiving less need for it after the sessions. This finding is consistent with research showing SDM can enhance self-confidence and skill in decision-making (Devi et al., 2020) and empower people with IDD to feel more in control of their lives (Martinis and Beadnell, 2021).

3. Facilitators made creative modifications to address participants' unique challenges, including using alternative modalities like PowerPoint presentations and introducing the SMART goal-setting approach. Facilitator memos indicate that the exercise converting a non-SMART goal into one that was specific, measurable, achievable, relevant, and time-bound (SMART) may have been especially effective. This is consistent with research and

Table 4. Paired t-test results comparing choice scores and each choice score component, pre-post intervention.

	Mean T1	Mean T2	T2-T1	*p*-value
Choice score	40.872	36.769	4.103	.002
Who decides what time you go to bed?	**1.154**	**1.026**	**−0.128**	**0.09**
Who decides which jobs you do around the house?	**1.865**	**1.595**	**−0.270**	**0.04**
When you cook dinner, who chooses what you cook?	1.897	2.026	0.128	0.45
Can you get yourself a drink or something to eat whenever you want?	1.154	1.154	0.000	1.00
What rules are there about using the telephone? Can you make a call whenever you want to?	1.193	1.115	−0.077	0.16
Who picks the staff to work in your house?	2.833	3.000	0.167	0.34
Who makes up the rules for your house?	2.240	2.320	0.080	0.68
Do you have your own key to the house?	1.760	1.600	−0.160	0.16
Who decides if you can have a pet [like a dog, a bird or goldfish]?	**2.171**	**1.943**	**−0.229**	**0.06**
Can you be by yourself in the house if you want to?	1.462	1.436	−0.026	0.78
Who works out your budget so you will have enough money?	2.053	2.053	−0.000	1.00
Who decides how much money you take out of your bank account?	1.917	1.972	0.056	0.69
When you buy your clothes who chooses which clothes to buy?	1.615	1.615	0.000	1.00
Who decides that you do or don't gamble? (Can you gamble if you want to?)	1.465	1.465	0.000	1.00
Does anyone go with you to see the doctor and the dentist?	2.231	2.179	−0.051	0.64
Who decided that you do or don't drink alcohol?	1.657	1.532	−0.125	0.47
Who decides if you exercise or play a sport?	1.081	1.027	−0.054	0.32
Does anyone stop you from going out?	1.462	1.359	−0.103	0.40
Who decides what you do in your spare time [when you are not working or at day activities]?	**1.282**	**1.103**	**−0.179**	**0.09**
Who decides if you can go to hotels and clubs?	1.750	1.813	0.063	0.69
Who decides if you can go and visit your family and friends?	1.740	1.482	−0.259	0.15
Does anyone stop you from looking at x-rated magazines, videos, or movies?	1.300	1.250	−0.050	0.71
Can you leave your job or day activity if you want to, do no work, and just stay at home?	1.834	2.034	0.200	0.22
Can you be late coming home from work or day activities?	1.903	2.033	0.129	0.16
Who decides if you want to take a day off from work or day activities when you are not sick?	1.742	1.645	−0.097	0.50
Overall, would you say that your life is free so you can choose what you want? All the time?	1.718	1.590	−0.128	0.28

Shown in bold are statistically significant results with a p-value < 0.1.

scholarship demonstrating that SDM is an individualized process based on the person's specific abilities and needs at a given time (e.g., Shogren and Wehmeyer, 2015).

4. The association between improved SDMI scores and the intervention tended to be stronger for participants under guardianship. This initial finding questions the common framing of guardianship and SDM as opposing approaches and instead suggests that SDM may be effective across different legal and support contexts, empowering individuals with IDD, even within guardianship arrangements (Kohn et al., 2012). This finding reinforces generally

that support is a positive resource that enables individuals to achieve goals, rather than something needed only when they cannot act independently (Shogren and Wehmeyer, 2015). One plausible explanation is that participants under guardianship may have experienced fewer baseline opportunities to practice decision-making independently, making the intervention a greater departure from their everyday experience. This interpretation aligns with SDM literature positioning guardianship and SDM not as mutually exclusive but as potentially complementary (Kohn et al., 2012). Consequently, SDM can be empowering precisely within contexts where legal authority has been delegated to another party (e.g., National Guardianship Association, 2017). Future research should explore this finding with larger and more diverse samples.

It is important to acknowledge the scope and limits of what this study evaluated. The SDM intervention comprised two components: (1) the structured weekly group sessions facilitated via Zoom and (2) the support that participants sought and received in their daily lives from family, friends, staff, and others outside of sessions. The outcome measures (participants' self-reported survey responses) reflect their perceptions of support and decision-making broadly. They do not isolate the contribution of the intervention from the naturally occurring support that participants may have received in their communities. Future research will need to employ methods that separately assess program-level and life-context dimensions of SDM.

Although the present intervention was developed and implemented in a U.S. legal and service delivery context, its core methodology of a structured, facilitator-guided SDM program grounded in individualized goal setting and support network development may offer transferable insights for researchers and practitioners comparatively. Countries that have ratified Article 12 of the UN Convention on the Rights of Persons with Disabilities are increasingly seeking such evidence-based SDM models (Pathare and Shields, 2012; Then et al., 2018). The Facilitator Guide and intervention structure developed in this study may be adapted for use in other national contexts, legal frameworks, and service delivery systems.

Goals set by the participants ranged from health improvement and pursuing hobbies to finding employment. Participants relied on a wide variety of supporters, including friends, family, other peers participating in the study, and paid staff, with similar success rates. Findings from the survey indicate that participants reported, on average, feeling more open to talking about their ideas, more supported in making decisions about their health and legal matters, and needing less support to rank options by their preferences after the intervention than before it. Further analysis by guardianship status suggests that the intervention's positive impact on SDMI scores may be more pronounced, and potentially more beneficial, for participants under guardianship.

Limitations

Despite its promising findings, this pilot study has several limitations that highlight the need for further rigorous research using additional participants across a range of settings. First, due to the COVID-19 pandemic, training sessions were conducted by Zoom. As such, there were some communication and technological challenges during the Zoom sessions, particularly in accommodating a participant who was deaf. Even with a signing facilitator and accommodations, conveying complex concepts like decision-making in familiar ASL signs proved challenging.

A related challenge arose from participants' having difficulty maintaining a position where the Zoom camera could capture their hand, arm, and facial movements while signing, which at times hindered communication and made it hard for the facilitator to interpret their responses. To address

this, we worked with the service provider, whose staff helped make the initial connections with participants and explained the study's purpose. Future research should consider providing this intervention in person and virtually to better accommodate some participants and to explore potential differences in outcomes based on delivery mode.

Second, this study was limited to eight weeks with a relatively small sample of participants; hence, it was unable to measure and observe longer-term impacts. Future research needs to consider implementing this intervention and others over a longer time period. For example, we envision a training course of 12 to 18 months to determine whether participants continue to use SDM over time, beyond the facilitation sessions, and whether SDM is associated with longer-term increases in self-determination and quality of life.

Third, this pilot study used a pre-test/post-test design to explore the feasibility of the eight-week intervention for goal setting and the use of SDM. As such, we cannot make causal statements regarding the impact of the SDM-based intervention on the outcome measures. Future studies should consider additional research methods and designs, using randomized controlled trial (RCT) studies to more closely examine the efficacy of the use of SDM training on quality-of-life measures, including self-determination, employment, community integration, and independent living, in addition to those measures included in this study. A body of study examining SDM training is needed, using randomized control trials and other multimethod approaches to identify individual outcomes from the training and other considerations (Arstein-Kerslake et al., 2017; Bigby et al., 2019; Douglas and Bigby, 2020; Morichi et al., 2025), as well as comparative study across a range of individuals with varying cognitive disabilities (Diller, 2025). These designs would allow researchers to establish with greater confidence the direction and degree of the association between the SDM intervention and outcomes of interest.

Fourth, this study evaluated a structured, facilitator-guided SDM program as an intervention. However, SDM as practiced by participants also extended beyond the sessions into their daily lives through interactions with supporters. The outcome measures reflect participants' self-reported perceptions of support and decision-making. The outcome measures thus do not isolate the contribution of the intervention from the support participants receive in their communities. Future research should consider study designs that separate program-level and life-context dimensions of SDM.

Finally, because this intervention was implemented with a relatively small sample of individuals with higher-functioning IDD, it limits our ability to determine whether a positive impact would be observed for other groups of people with IDD who might differ from our sample. Participants in this study were able to communicate verbally or through sign language and participate in group discussions via Zoom. Accordingly, our findings should not be generalized to the full spectrum of IDD. However, the fact that the intervention was feasibly delivered during the COVID-19 pandemic, a period of significant disruption to services and daily routines, suggests that it may be robust across challenging implementation conditions. Larger-scale SDM projects, involving a broad and diverse range of program partners and participants, are needed to identify and address the unique characteristics and needs of people with IDD across geographical areas, as well as assess the impact of the intervention on population sub-groups.

Conclusion

The exploratory research in this study provides initial evidence that an eight-week SDM program is feasible for adults with higher-functioning IDD who can engage in group-based sessions and that it may be associated with improvements in SDM-related outcomes for this population. In addition to

this pilot program, we are developing a toolkit to assess whether over time such an approach may assist other participants apply SDM in their daily lives. Future research is needed to evaluate these and other initiatives and to engage diverse participants over extended periods in identifying best practices for implementing SDM. Lastly, study is needed on SDM training best practices, as well as partnerships with service providers, facilitators, and other stakeholders, on the promise of SDM to support broad and meaningful self-determination across the lifespan from young to older ages.

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Ethical considerations

This study was approved by the Institutional Review Board at Syracuse University.

Consent to participate

All participants, or their legally authorized representatives when applicable, provided informed consent prior to participation in the study.

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Declaration of conflicting interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The views expressed do not necessarily reflect the official policies of NIDILRR, ACL, or HHS, nor do they imply endorsement by the U.S. Federal Government.

Data Availability Statement

The data as well as the code for data cleaning and analysis associated with the current submission is available upon request.

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