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Promoting Self-Determination in Community Contexts: Experiences with Implementing the  
Self-Determined Learning Model of Instruction

### **Abstract**

This paper describes a pilot project focused on creating opportunities for self-determination to enhance the community participation outcomes of adults with intellectual and developmental disabilities (IDD) using the Self-Determined Learning Model of Instruction (SDLMI). The pilot project grew out of a partnership between researchers at a university and the state's developmental disabilities services system in their state and emerged from collaborative discussions of needs in the community. The purpose of the project was to (a) investigate effective ways to deliver the SDLMI in a community context and (b) identify the systemic changes needed to enable scaling-up of supports for self-determination. This paper introduces a framework for implementing the SDLMI in the community and highlight lessons learned through community-based implementation.

Key words: Self-Determination, Community Participation, Adult, Intellectual Disability, Goal Setting and Attainment

Causal Agency Theory defines self-determination as a “dispositional characteristic manifested as acting as the causal agent in one’s life” (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015). National and international disability policy emphasizes the importance of self-determination in enhancing community living and participation outcomes. For example, in the United States, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (2000) emphasizes the right to self-determination as well as community integration and participation. Internationally, Article 19a of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) emphasizes the right to self-determination in community living stating that “persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement” (p. 15). Article 26 of the UNCRPD further connects self-determination with the right to inclusive education and employment as well as the right to marry, express opinions, and choose modes of transportation that fit needs (United Nations, 2006). As such, disability policy emphasizes the critical need to support self-determination in the context of community participation. However, despite these long-standing policy mandates, there remain significant barriers to self-determination in the day-to-day lives of people with disabilities. The impacts of these barriers on community participation outcomes are wide-reaching. For example, researchers have found that people with intellectual and developmental disabilities (IDD) (a) participate in fewer community activities than their peers without disabilities (Hammel et al., 2015; Sheppard-Jones et al., 2005), (b) report being socially isolated and lonely in their communities (Gilmore & Cuskelly, 2014), and (c) rarely have opportunities to build careers aligned with their preferences and values (Butterworth et al., 2015; Winsor et al., 2018).

### **The Need for Enhancing Self-Determination and Community Inclusion**

Systemic barriers exist within disability service systems and community contexts that limit opportunities for adults with IDD to develop and use self-determination abilities in their day-to-day lives. For example, support professionals, including direct support professionals (DSPs) and case managers, often lack the training and administrative support to create opportunities for the development of self-determination abilities (Hewitt et al., 2013). Further, DSPs rate caregiving tasks as a higher priority than tasks that promote community participation and self-determination, suggesting a systemic valuing of caregiving over promoting self-determination (McConkey & Collins, 2010). These systemic issues have created a system of supports for adults with intellectual disability where opportunities for self-determination are frequently and artificially restricted in community living settings (Nonnemacher & Bambara, 2011; Shogren & Broussard, 2011). These barriers necessitate new approaches to provide supports for adults with IDD that promote change at the personal as well as organization/system level to (a) build self-determination abilities, (b) create opportunities for the expression of self-determination across environments, and (c) lead to more individualized supports for self-determined lives in the community (Shogren, Schalock, et al., 2018).

Specifically, there is a need for systems to “design and implement support strategies that are aligned with the contextual factors that influence the person and that lead to enhanced human functioning and valued personal outcomes” (Shogren, Luckasson, et al., 2018). In doing so, systems must support the development of evidence-based intervention models that can be effectively delivered (and reimbursed) in community contexts. This is particularly important when working to build self-determination abilities as most, but not all, self-determination intervention research has occurred in schools. There is a need for more focus on how to

implement self-determination interventions effectively in community contexts (Luckner et al., 2019). However, as noted previously, organization and system level changes that prioritize self-determination and community participation are also needed.

The purpose of this paper, therefore, is to describe a pilot project focused on creating opportunities for self-determination to enhance the community participation outcomes of adults with IDD using the Self-Determined Learning Model of Instruction (SDLMI; Shogren et al., 2019). We introduce a framework for implementing the SDLMI in the community, as much of the previous research and practice has focused on school contexts (Hagiwara et al., 2017), and highlight lessons learned through community-based implementation. The pilot project involved two universities and one state's developmental disabilities services system. The overall intent of the project was to (a) investigate effective ways to deliver community-based interventions designed to enhance opportunities for self-determination and community participation of adults with IDD and (b) identify the systemic changes needed to enable scaling-up of supports for self-determination in a sustainable, meaningful, and feasible way through state developmental disability service systems. Documenting the lessons learned from this pilot project is the first step in ongoing work focused on establishing the impact of delivering the SDLMI in community contexts on community participation and self-determination outcomes.

In the following sections, we describe the intervention used in this pilot project, the SDLMI, defining its core components as well as specific implementation supports for the delivery of the SDLMI in community contexts. We next provide an overview of the pilot project, describing contextual considerations and lessons learned from implementing the SDLMI in the community. Finally, we discuss next steps for future research and practice focused implementing

the SDLMI in the community to enhance self-determination and community participation outcomes.

### **The Self-Determined Learning Model of Instruction (SDLMI)**

To address the need for evidence-based intervention models, this project adopted Causal Agency Theory (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015) as the theoretical framework to guide intervention selection and implementation. Causal Agency Theory highlights importance of (a) building self-determination abilities, (b) creating opportunities for the expression of self-determination, and (c) individualized supports that enable self-determined lives. Given the established relationship between self-determination and valued outcomes, including community participation (Shogren, Wehmeyer, Palmer, Rifenbark, et al., 2015), the SDLMI was developed to align with Causal Agency Theory and address the need for supports that build abilities and create opportunities for self-determination. The SDLMI has been recognized as an evidence-based instructional model in the transition from school to the adult world (National Technical Assistance Center on Transition, 2016), but was designed to be used across the life course. The core components of the SDLMI were developed to be implemented in any context (e.g., home, school, community) to enable people with IDD to become more involved in, and ultimately direct the goal setting and attainment process.

Implementation of the SDLMI involves a three-phase instructional process (Phase 1 - What is my goal? Phase 2 - What is my action plan? Phase 3 - What have I learned?), implemented by a trained facilitator and repeated over time to promote enhanced opportunities and growth of self-determination abilities. The model focuses on building abilities and creating opportunities for self-determined, goal directed actions. People with IDD grow in their abilities to: decide (e.g. learn about strengths and areas of need, set goals based on a vision for the future),

act (e.g. solve problems encountered while working towards goals, think about different pathways to navigate through barriers encountered), and believe (e.g. feel empowered to reach goals, know one can make changes and be supported their life) as they set and attain goals (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015). The SDLMI is defined by three core components embedded in each of the three phases: *Person Questions*, *Facilitator Objectives*, and *Educational Supports*.

Each phase of the SDLMI poses a problem for the person with IDD to solve related to their community participation and during each phase, facilitators teach and create opportunities for the person using the model to work through four *Person Questions* (12 questions total) that differ from phase to phase but represent identical steps in the problem-solving sequence, and enable the person to identify: (1) the problem, (2) potential solutions, (3) barriers to solving the problem, and (4) the consequences of each solution. Each *Person Question* is linked to a set of *Facilitator Objectives*, which guide the facilitator to enable and support the person to answer the questions. The *Educational Supports* are specific supports that facilitators can use to address the *Facilitator Objectives*. It is important to note that the SDLMI is designed to be used repeatedly. In Phase 3, as the person with IDD answers the question “What have I learned?”, the person will reflect on their goal and action plan and decide if a new goal needs to be set or a new action plan is needed to address the same goal. Through this cyclical process, the person internalizes the problem-solving sequence and builds skills related to self-determination that can be generalized across contexts and goals. The SDLMI supports the person to grow in their self-determination abilities over time as well as creates opportunities for systems to support the expression of self-determination by creating contexts that support the express self-determination in various life domains.

In SDLMI implementation, facilitators are trained to act as supporters and advocates for self-determination, not as the expert – the expert is the person. The role of the facilitator is to use the Facilitator Objectives and Educational Supports to enable the person to grow in their self-determination abilities as they respond to the Person Questions. Therefore, the person with IDD engaging in the SDLMI is the goal setter and problem solver, and the facilitator is the supporter. Other key supporters in the person’s life (such as DSPs, job coaches, case managers, family members, friends, community members) must also be engaged in learning about the goals being set by the person with IDD as they are central to creating the opportunities and supports for the person to exercise their self-determination.

As mentioned earlier, the SDLMI has been used with people with and without disabilities across contexts (e.g., school, community) and can be implemented for any type of goal (e.g., academic instruction, transition planning, community activities). However, to meet demands and expectations of different implementation contexts, implementation supports are tailored to maximize the ability of facilitators to deliver of the SDLMI, particularly as the role of a facilitator as a supporter and advocate rather than the expert differs from other intervention approaches. Table 1 differentiates between the core components of the SDLMI (which remain the same in all contexts) and implementation supports (which are tailored to fit the context). The implementation supports used in this pilot project will be described further in subsequent sections.

<Insert Table 1 about here>

A wide body of research (Hagiwara et al., 2017) suggests a positive impact of implementation of the core components of the SDLMI in school settings. For example, the SDLMI has been implemented in large-scale randomized controlled trials in school settings and



has consistently been found to enhance self-determination in students with disabilities (Hagiwara et al., 2017; Shogren et al., 2020; Wehmeyer et al., 2013). Further, emerging research that guided this pilot project has suggested that these core components are effective across contexts, when effective implementation supports are provided, when facilitators and supporters are trained in on enhancing self-determination, and when organizations and systems create supports for meaningful implementation. For example, a modified version of the SDLMI, the Self-Determined Career Design Model (SDCDM), which utilizes the same core components as the SDLMI, has been used to support adults with intellectual disability to enhance employment outcomes and attainment of career goals in adult service system contexts (Dean et al., 2017; Dean et al., 2019; Shogren et al., 2017). Findings from a randomized control trial that trained DSPs as facilitators in adult service systems across one state found that adults with IDD who worked through the SDCDM increased their self-determination and goal attainment (Shogren et al., 2016). However, systemic barriers limited sustainability of the intervention, including a lack of opportunities and supports for adults with IDD to exercise self-determination outside of SDCDM sessions and a lack of time and training for DSPs. These findings informed the implementation of the current pilot project, including the focus on (a) partnering and co-planning with the developmental disability services system; (b) exploring how to innovate in the use of the SDLMI in the community; and (c) identifying systemic changes needed to enhance feasibility, usability, and impact in the long-term.

### **Description of Community Implementation of SDLMI: Pilot Project**

As described earlier, the purpose of the pilot project was to explore innovative ways to promote meaningful, self-determined community participation outcomes for adults with IDD supported by a state developmental disabilities services system. The collaborating organizations

came together around a shared belief in the importance of self-determination for adults with IDD as well as the need for systemic change to enable self-determination and meaningful community living and participation in the current system. The current pilot project built on an ongoing partnership between researchers at one of the universities and the state developmental disabilities services system that included multiple research and program collaborations focused on improving the lives of individuals receiving Medicaid-funded Long-Term Supports and Services (LTSS) and their families (Jones & Gallus, 2016; Jones et al., 2018). The pilot emerged from collaborative discussions of needs in the community, with a vision for promoting community-based implementation of the SDLMI using trained facilitators from one of the universities. Further, the research team established a goal of establishing feasibility of community-based implementation of the SDLMI as well as exploring ways to enable in the long-term reimbursement for such services. Initial planning for the project occurred throughout the Fall of 2019, which culminated with a one-day workshop on self-determination and SDLMI for facilitators and other interested stakeholders (described below). Implementation of the SDLMI began in January of 2020 and concluded in April of 2020, which was earlier than planned due to the COVID-19 pandemic.

### **Preparing for Implementation**

Prior to initiating the pilot, a one-day informational workshop on self-determination and the SDLMI was facilitated by one of the universities. Nine leaders from the developmental disability services agency, two administrators from adult support provider agencies that provided Home and Community Based Services (HCBS) to adults with IDD that were participating in the pilot, six researchers from the two universities (including researchers from the university that developed the SDLMI), and two university students who would act as SDLMI facilitators participated. For this workshop, since most attendees would not serve as facilitators, the standardized two-day facilitator

training for the SDLMI implementation was modified to focus on (1) educating stakeholders about self-determination and core components of the SDLMI; (2) coming to a consensus on the stakeholders' future systems-level vision for self-determination intervention and supports (i.e. enabling adults with IDD to direct their community participation based on their strengths, interests, and beliefs); and (3) brainstorming ways state leadership and provider organizations could provide organization/system level supports for implementation of the SDLMI as the university facilitators delivered personal supports to enhance goal directed actions of the adults with IDD through the SDLMI.

The two university students who attended the workshop were identified as facilitators for the SDLMI and received ongoing training and coaching throughout the project from the SDLMI developers. One of the students had participated as a facilitator in a previous project using the SDLMI and was familiar with the concept and the structure of the SDLMI. In the previous study, the SDLMI was used to facilitate goal setting, action planning, and self-reflection during an inclusive community walking program for adults with IDD and university students (Tucker et al., 2020).

### **Implementation Supports for Facilitators**

To enable implementation of the SDLMI in the community, specific implementation supports customized to community-based delivery were used. As shown in Table 1, the core components of the SDLMI remained the same, but the specific implementation supports were used. This included targeted training materials for facilitators that used community-examples; resources including PowerPoints, SDLMI Activity Sheets that referenced community examples; as well as Goal Notebooks appropriate for adults with IDD to facilitate communication with supporters outside of SDLMI sessions. These were adapted from materials initially developed for and effectively utilized at school settings (Raley et al., 2018). Also, throughout implementation, the facilitators

participated in weekly, virtual coaching meetings based on the SDLMI Coaching Model (Hagiwara et al., 2020), which were led by trained SDLMI coaches from the SDLMI university team. One-hour coaching meetings were essential to promote fidelity of implementation and focused on 1) problem solving SDLMI implementation with adults with IDD in the community, 2) modeling use of implementation materials, 3) reviewing implementation materials for community context, and 4) brainstorming contextual supports and barriers to self-determination specific to the pilot project. For example, based on feedback from the facilitators in the early stages of the pilot project, the SDLMI university team modified implementation materials (e.g., Session PowerPoint presentations, SDLMI Activity Sheets) to include more targeted visual cues and familiar examples based on the needs and interests of the participants in the project.

Further, the coaching meetings were used as a way for mentors to directly enhance facilitator fidelity of implementation. Consistent with the coaching model developed for the SDLMI (Hagiwara et al, 2020), coaches observed SDLMI sessions monthly and used a fidelity rating form adapted from a fidelity form developed for the SDLMI in school settings (Shogren & Raley, 2018). The SDLMI Fidelity Measure contains three sections focused on (1) general observation information based on the session the coach is observing (e.g. targeted Person Question and Facilitator Objectives) as well as the facilitator's perspective on the session, (2) session content of the SDLMI (e.g. degree to which targeted Person Question and Facilitator Objectives were addressed), and (3) core content (e.g. the degree to which facilitator refers to participants' goals or provides educational supports). Coaches use the fidelity rating to guide their observation of SDLMI sessions and then use the fidelity rating to structure coaching sessions.

### **Pilot Participants**

Adults (18 years of age and older) with intellectual and developmental disabilities who received Home and Community Based Services (HCBS) through a partnering provider agency and who expressed interest in participating were recruited and screened by a research team member for eligibility. Inclusion criteria included: 1) available and willing to commit to 1 to 2 training sessions per week (1-2 hours/week) 2) able to provide meaningful self-report by answering questions about his/her daily activities and feelings independently or with minimal help from a trained research team member. Informed consent/assent was obtained for all participants prior to participation, and when required, consent was also obtained from the participant's legal guardian.

Two groups of four adults (six males, two females) with IDD ages 29 to 77 ( $M = 49.5$ ;  $SD = 20.2$ ) voluntarily participated in the pilot. Participants met with the facilitators to work through the SDLMI twice a week for one hour. Table 2 describes demographic information for each participant. The eight participants all lived in their communities, but in diverse settings, including small group homes (setting includes 2-3 individuals receiving waived services), medium-sized group homes (setting includes 4-8 individuals receiving waived services) and in their own apartment with or without roommates. All participants were supported by the same residential service provider but had unique direct support staff. Employment for participants varied and included the local sheltered workshop ( $n = 5$ ), a part-time community job on the university campus ( $n = 1$ ), retired ( $n = 1$ ), and unemployed ( $n = 1$ ). Five participants set goals to obtain competitive integrated employment, two participants set goals to enhance health and wellbeing, and one person set a goal to enhance their education.

### **Pilot Implementation**

The implementation plan for the pilot included 32 sessions from November 2019 to April 2020. The first 12 sessions were designed to build rapport among the facilitators and all group members. Facilitators used the *Finding Me* (Ober, 2018) guidebook to gather baseline assessment of participants' self-awareness, interests, and needs and to assist with building group rapport prior to beginning the SDLMI. *Finding Me* included sessions covering a range of personal topics (e.g., Where I Live; People I Know and Care About; My Strengths, Interests, and Hobbies; My Dream for My Life). Following *Finding Me*, 20 sessions were planned for SDLMI implementation, including four Preliminary Conversation sessions which the facilitators introduced the concept of self-determination and how the SDLMI works, 12 sessions for the Person Question (one session for each Person Question), and additional sessions for review and presentations, consistent with the implementation of the SDLMI core components across settings.

Each in-person session was structured similarly to enhance group participation and create a routine. Each session began with around 5 minutes to chat about people's week as an effort to further get to know the participants along with a brief mindful breathing exercise and opening mantra co-created by group participants. SDLMI sessions began with a description of terminology aligned with the Phase of the SDLMI that participants were engaging in (e.g. short-term and long-term goals, goal attainment, problem solving), followed by a small group discussion where the facilitator worked to achieve each of the Facilitator Objectives, which led to each person answering the Person Question for the day, recording responses in Goal Notebooks, and a brief review at the end of activities that participants would engage in prior to the next session. The lessons and small group discussions were structured to engage group

members in conversation. For example, when defining long-term goals, the facilitators provided examples of their long-term goals and would ask group members about theirs.

**Impact of COVID-19.** The project began as planned, but the onset of the COVID-19 pandemic in the spring of 2020 led to significant disruptions in project activities. At the time public health measures were required to reduce the spread of the COVID-19, 14 in-person SDLMI sessions had been completed. The primary focus of participants' goals included participation in a broad range of community activities. Participants had worked through Phase 1 – What is my goal?– and were in the middle of Phase 2, working to develop action plans to achieve their goal.

COVID-19 required rapid decision making about ongoing study implementation procedures. Public health recommendations led to university IRBs requiring the cessation of in-person research in early March of 2020, with the option to transition to remote sessions using videoconferencing software. Through much discussion and consultation with participants and their residential service provider, multiple logistical and ethical issues emerged. First, several participants did not have reliable access to technology for the sessions, consistent with research suggesting limits and restrictions on technology access for adults with IDD living in community-based residential settings (Chadwick et al., 2013; Lussier-Desrochers et al., 2017). Second, and even more problematic, stay-at-home orders from local and state governments in response to the COVID-19 pandemic meant that participants' opportunities and supports to engage in their community were limited, particularly in relation to goals that were set during Phase 1 of the SDLMI explicitly focused on community participation. For example, it would have been impossible for participants to access the community locations (e.g. workplace, gym) needed to develop and enact action plans they were developing during Phase 2 sessions, even if session

were virtual. The other option would have been to restart with Phase 1 of the SDLMI and support participants, virtually, to set a new goal and begin action planning. However, this would have been challenging due to the many unknowns about feasibility of goals requiring access the community in the short and long-term. Any potential modifications may have negated participants' work of setting initial goals, and was further complicated by conflicting information and supports available to enable people with IDD to understand and navigate the pandemic and its impact on their lives and supports (Boyle et al., 2020; Courtenay & Perera, 2020). As such, we made the difficult decision to cease implementation of the SDLMI and data collection, and instead focus on lessons learned from the planning for and implementation of the first 14 SDLMI sessions to inform future work.

### **Lessons Learned from SDLMI Community Implementation**

Of the eight group members who participated in the pilot project, six attended all 14 SDLMI sessions offered prior to COVID-19. When the remaining two participants missed sessions due to illness or schedule conflicts, one-on-one sessions with facilitators were offered enabling ongoing participation in subsequent group sessions. Although the participants were of varied ages, living and employment arrangements, and life experiences, all participants identified goals they wanted to set to enhance their lives and reported benefiting from hearing feedback and interacting from others. All participants showed excitement and communicated enthusiasm during and after for each session and completed Phase 1 by setting goals aligned with their strengths, interests, and needs. Four group members set goals related to integrated employment in the community (e.g., *I want to work at Walmart, I want to get a new job*). Three participants set goals related to improving their health (e.g., *I want to exercise more, I want to be able to walk around the park*), and one set a goal related to personal growth (i.e., *I want to learn to*



*read*). Although the attainment of goals is unknown because of COVID-19, all participants began to think about action plans (Phase 2) and generate ideas both for what they could do to take steps toward their goals and what barriers they might encounter. One participant noted that the SDLMI helped them to “figure out a little bit about how maybe to set the goals and maybe now try more.” They emphasized that they could think about “trying to do it in smaller steps than you know just all at once or whatever.”

However, there were several systemic barriers that emerged and impacted the feasibility of sustained and scaled-up implementation of the intervention model. In the sections that follow we further describe systemic issues that must be address to inform ongoing, community-based SDLMI implementation, including: (a) transportation; (b) considerations for selecting facilitators to support the development of self-determination abilities; (c) efforts to communicate SDLMI goals, action plans, and support needs with key supporters across environments; and (d) systemic barriers to accessing opportunities and supports to exercise self-determination (as highlighted by a case description).

### **Transportation Challenges**

At the start of the pilot, including during *Finding Me* sessions, immediate complexities with organizing reliable transportation to enable participants to be at group sessions emerged. Despite all participants being supported by the same residential services provider (although none of the participants lived in the same residence) coordinating transportation was highly challenging and there were often issues with late arrival or departures from sessions that added additional demands for facilitator time and coordination. Ongoing challenges were experienced across sessions, and systemic ways to reduce this barrier must be considered if group-based

SDLMI implementation in the community that brings together diverse community members with IDD is scaled-up.

### **Facilitator Considerations**

In this pilot project, university students served as facilitators, which offered advantages, such as prior experience implementing the SDLMI, rapid access to the research and SDLMI development team to troubleshoot implementation challenges, and dedicated time to focus on planning for sessions. Further, as the students had advanced training on supporting people with IDD, implementing evidence-based interventions, and engaging in ongoing professional development and coaching, they were prepared to implement the SDLMI with fidelity, ensuring the core components were implemented as intended. Additionally, the facilitators were not influenced by previous goals or expectations within the LTSS system for the participants and could support participants based solely on the individual's identified strengths, interests, and support needs. However, we also learned that using facilitators outside of the service system created challenges as the facilitators did not know the participants before this pilot project, necessitating significant rapport building and learning about strengths, interests, preferences, and needs. The *Finding Me* guidebook and general conversation time each session were built in as a way for facilitators and group members to get to know each other. However, once implementation of SDLMI began the facilitators learned that a few minutes each session was not long enough, and the participants reported a desire for more personal interaction time that was not feasible in the implementation schedule.

### **Communication Challenges**

Another challenge, however, in having a facilitator that was outside the provider organization, was ensuring meaningful communication about SDLMI activities (i.e. goals set,

strengths and barriers identified, action plans created) to the service provider organization and the array of supporters (e.g., DSPs, case managers, job coaches, family members) that were not part of SDLMI sessions. Each participant also had a complex array of informal and formal supports and services, which is positive. However, facilitators faced challenges with supporting participants to navigating this array of supports as they engaged in SDLMI-related activities outside of sessions, such as enacting their plan to visit potential employment sites based on the person's interests. For example, one participant who was working at a sheltered work program part time at the time of the study set a goal related to working with the university's athletic team because he had been a big fan of the university football team. This goal needed to be communicated to supporters at work; however, the facilitators were unsure of how to support participants to communicate with the correct person (i.e. should they talk to a job coach from VR, or should they talk to their case manager?). The facilitators used SDLMI Goal Notebooks to record participants' goals and action plans created during SDLMI sessions. The purpose of the Goal Notebooks were to support participants to communicate their goals and action plans with supporters who could support them to enact their plans. Participants were asked to share their Goal Notebooks with their supporters, however this typically only reached DSPs in the home, while case managers, job coaches, and others needed to be aware of and supportive of the goals and action plans. Additionally, if not disrupted by COVID-19, it is likely even more complex issues related to the implementation of action plans that required supports outside of SDLMI session would have emerged. For future implementation, it will be critical to carefully design and plan strategies to utilize support networks, including families, friends, and professionals to enhance community participation and work toward self-selected goals. Determining how to enhance communication and understanding of goal development and implementation across multiple

stakeholders within provider organizations, communities, and service systems will be critical to enable the change needed to promote community participation in ways valued by the person with IDD. This has implications for systemic changes needed to (a) infuse communication about self-determination instruction that is occurring throughout each person's individualized system of support and (b) promote greater focus on self-determined goals across environments (e.g., raising expectations for exploring career options, accessing diverse community environments, etc.) based on each person's interests, not provider organization's needs.

### **Self-Determination Opportunity and Support Challenges**

Beyond communication challenges, the challenges participants faced in attempting to navigate the complex systems of supports in their lives as well as access supports and opportunities to identify and work toward their goals highlight the critical need for formal and informal supports to have an understanding of self-determination and the SDLMI. Participants were not always able to get the supports needed to go after their goals set during SDLMI sessions. One participant's experiences highlight these challenges. This female participant was in her 70s and worked at a sheltered workshop at the time of the study. When working through the Phase 1 of the SDLMI, she expressed an interest in finding a job at Walmart that involved shelving. She listed her strengths as being strong, staying on task, and putting things on the shelf, while she recognized that one of her areas of need was to improve skills understanding how to plan for stocking shelves. She enthusiastically came up with ideas to enhance her strengths to become more efficient at stocking shelves that were both creative and feasible, with the right opportunities and supports. Therefore, for Person Question 4: What can I do to make this happen?, she decided to set a goal to talk with her job coach at the workshop (one of the supports that she listed for Person Question 2: What do I know about it now?). She also identified a need

to advocate for new responsibilities at the workshop to prepare her for the job that she was interested in getting at Walmart. To enact the action plan she began to create in Phase 2, prior to sessions ending due to COVID-19, the participant talked with her job coach and shared her goal of getting a stocking job at Walmart. The participant then talked with her case manager to request additional responsibilities in the workshop. However, the case manager was reluctant to support the participant's request for additional responsibilities because the case manager felt that the participant had not always actively engaged in past opportunities for job exploration. The SDLMI facilitators were told, therefore, this was not an option, and the individual could bring it up at a future team meeting.

While it is possible that the participant may have been disengaged in previous job exploration, that does not negate her right to explore job options now, particularly for competitive, integrated employment. However, the responses from her service providers to a goal set through the SDLMI highlight the barriers that are often present in systems for supporting self-determination, particularly when a person with IDD identifies a goal that requires the restructuring or rethinking of existing supports. For example, the service providers appeared to lack understanding of the focus of the SDLMI and the importance of exploring interests and needs, including interests and needs that can change over time. This participant identified a goal and created an action plan that could potentially lead her to her desired outcome of integrated, competitive employment doing a job she was expressing an interest in and identify that she wanted to and needed to build more skills at to be successful. However, these interests were not celebrated and supported, but instead limited by previous experiences and schedules for meetings and revising goals. Further, there were not clear lines of communication to bring together a team (e.g., job coach, case manager, other supporters) to support the implementation of needed action steps and even possible revision of the goal, if further

work through the SDLMI (i.e. Phase 3: What have I learned?) revealed the goal was in fact not well aligned with interests. This highlighted the need to promote training across all levels of the service system and to create opportunities for communication, particularly about the purpose of the SDLMI as a key focus is to explore the person's goals. Training in the SDLMI and how other supporters (in this case, case managers) can enable opportunities for exercising self-determination is critical for future implementation in the community to make sustained and lasting change at the individual and system level.

This also brings up the need to consider ethical issues in SDLMI implementation in community settings, namely, the role of systemic barriers that limit the ability of people with IDD to apply and actualize their self-determination skills across contexts. Like the decisions made around COVID-19 in the pilot project, namely that it was not ethical to continue to deliver SDLMI instruction if the goals could not conceivably be achieved because of the pandemic, similar issues emerge when supports are not in place for self-determined actions across adult environments and supports.

### **Considerations for Implementing the SDLMI in the Community**

As described above, building systems of supports for adults with IDD is complex and often involves coordination among multiple people, organizations, and systems across different life domains. This creates significant opportunities for the development of effective systems of supports that promote the outcomes targeted in disability policy (Shogren, Schalock, et al., 2018); however, there remain significant barriers that are highlighted in existing literature and all too often lead to systems maintaining the status quo in supports and services, thereby limiting self-determination and community participation outcomes (Shogren, Luckasson, et al., 2018). To effectively implement the SDLMI in the community, there is a need not only for effective,

person-level interventions and supports that can be used to enable people with IDD to grow in their self-determination abilities but also for systemic change that lead to greater opportunities and supports for self-determination within provider organizations, communities, and larger disability service systems. For these reasons, supports must be planned for and integrated at the person-level as well as at the organization and system level.

In the sections that follow, we highlight key issues – phrasing these issues as questions - that should be considered in research, policy, and practice at the person and organization/system level to advance supports for self-determination and enhance community participation outcomes, building on a framework developed by Shogren, Luckasson, et al. (2018) to use contextual analysis to promote the ability of systems to design and implement support strategies that lead to valued personal outcomes.

### **Personal Level Supports**

**Who Serves as Facilitators?** Given the large number of organizations and systems a person interacts with, who is best positioned to act as facilitator of the SDLMI? To answer this question, teams must consider several factors, such as how SDLMI sessions will be delivered, the level of training necessary to serve as an SDLMI facilitator, and the degree to which facilitation of the SDLMI fits within the job description of the person. Previous research has experimented with using facilitators from different roles within the support system. For example, in one study DSPs were trained as facilitators (Shogren et al., 2016). DSPs generally have almost daily contact with people with IDD and usually know a great deal about the support needs of the people they serve (President's Committee for People with Intellectual Disabilities, 2017). They are therefore well positioned to be facilitators of the SDLMI. However, DSPs generally do not have training in teaching skills related to self-determination, meaning that DSPs, may require

additional training and coaching to learn to deliver a complex intervention with fidelity (Cudré-Mauroux et al., 2020; McConkey & Collins, 2010). Additionally, frequent turnover is common with DSPs (President's Committee for People with Intellectual Disabilities, 2017), therefore consistency for long-term implementation of the SDLMI should be considered. Further, DSPs may not be connected to all the various service systems that a person interacts with in the same way as a case manager or someone who is tasks with managing systems of support.

Utilizing facilitators from outside of the service delivery system is another option that offers advantages and disadvantages. One project utilized Occupational Therapy students as SDCDM facilitators (Dean et al., 2019). In this study, the students were doing internships at an organization that supported adults with IDD. The students had previous training in teaching skills related to self-determination, however, were only at the organization for three months. Therefore, careful planning was needed to provide continuity in SDCDM delivery between one student and the following student. Additionally, the students had little access to participant's support networks, much like in the current study. Creation of additional supports, however, may not always be the role of a facilitator and can even distract from SDCDM or SDLMI delivery if too much focus is put on what supports are available, instead of what supports are needed. Aside from students, other trained facilitators from outside of the LTSS provider network, such as community members, mental health professionals, or others could also be considered based on the degree to which they could effectively organize and implement group-based SDLMI activities with training and coaching. However, a plan for how facilitators will communicate with key stakeholders will still be critical, as well developing the buy-in and support from administrators in provider organizations and service systems for such communication.

The selection of the facilitator will also necessitate consideration of the existing



relationship or lack thereof between a SDLMI facilitator and participants with IDD. Key to SDLMI implementation is establishing a trusting relationship between the facilitator and the participant with IDD, particularly to establish the support and advocate role of the facilitator. In our pilot project, this was why we added the *Finding Me* guidebook to enhance these relationships, prior to beginning the SDLMI. In other settings, like schools, teachers spend considerable amounts of time building relationships with students over the course of the school year. Case managers and DSPs may have more established relationships but may not be familiar with serving in the role of a facilitator, consistent with the SDLMI. Thus, in community settings, some relationship building sessions may be needed, particularly when the facilitator has not previously interacted with participants or when the facilitator needs to take on a different and new role.

**Where Does SDLMI Implementation Occur?** Another consideration for planning is where SDLMI implementation will occur. Key factors in making this decision are (a) does instruction occur in a group or individual format; (b) does instruction occur in-person or remotely, and (c) how can reliable modes of transportation be established for in-person, group sessions to enable participants to attend SDLMI sessions? For individual sessions, a participant and facilitator can more easily decide on a place to meet (e.g., participant's home) which could offer a private, relaxed setting with access to key supporters. However individual sessions do not offer the group learning and support that can be powerful in group sessions. However, for group sessions, locations where all group members will have access need to be considered, such as community centers, libraries, universities, or support provider spaces. Additionally, specific preferences of group members, such as sensory preferences should also be considered, as well as privacy and comfort with communication about one's goals and visions for the future in public

settings. Further, ensuring that reliable transportation options are available will be critical, as missing sessions or arriving late can disrupt the group-learning. Remote facilitation is also an option, as this would make it possible to train and utilize facilitators across regions that could deliver one-on-one or group sessions. However, there are logistical challenges with remote facilitation that will need to be addressed, as we learned in the pilot project during the onset of COVID-19, including access to devices and the internet. Remote facilitation will require additional planning for relationship building, knowledge of resources in a given locale if the facilitator is not there, and communication supports to enable participation by those with complex communication needs.

### **Organization and Systems Level Supports**

**What Community Resources can be Leveraged?** Community resources outside of the adult service system should be part of any individualized systems of supports. Leveraging these resources, however, to promote opportunities and supports for self-determination has not been fully explored in previous research and practice (Soresi et al., 2011). Understanding the range of resources available will be important for SDLMI implementation in the community, and contextual analysis could be used to identify organization, community, and system resources and inform planning for communication across stakeholders (Shogren, Luckasson, et al., 2018). For example, this pilot project utilized resources from a local university (meeting rooms, researchers to lead the project, and students to facilitate the SDLMI) to support implementation. Previous projects have also utilized university researchers and student facilitators to implement the SDCDM (Dean et al, 2018; Dean et al., 2019). But other community resources should be considered. For example, Centers for Independent Living (CILs) are community organizations that support community living and independence for people with disabilities. CILs have access to tools, resources, and supports for people with disabilities to integrate into their community,

which is consistent with many goals set by participants with IDD during the SDLMI process (Wehmeyer & Gragoudas, 2004; White et al., 2010). CIL employees, who often have lived experience with disability, could be ideal facilitators of the SDLMI in some circumstances, but could also be key supporters as participant set and go after goals. Self-advocacy groups should also be explored as well as other non-disability community and organization resources, such as Parks and Recreation Departments or Workforce Development Centers.

**How to Build Communication and Collaboration?** As more community resources and systems are involved, it will be important to consider how to raise awareness in formal and informal support systems about self-determination and how to ensure that key-decision makers understand the SDLMI and the role of organizations and systems to creating opportunities and support for self-determination. Bringing organizations together to develop a plan for how to coordinate services and communication with all members of a support network during SDLMI intervention will be critical. As noted in pilot implementation, challenges related to communicating across organizations arose during implementation can emerge as can challenges with low expectations or a lack of recognition of the right of people with disabilities to self-determine their own lives. Support providers are key to providing opportunities and supports for exercising self-determination, as well as for identifying and leveraging opportunities and supports to enable people to identify and go after a wide range of goals. This necessitates systems level thinking about how to embed SDLMI implementation across contexts as well as to identify and foster “champions” for self-determination initiatives within communities provider organizations. Further, people with IDD should be actively engaged in setting the agenda for organization and systems change and should have the opportunity to advocate and challenge the system to provide supports in the manner that is aligned with their personal values and

preferences.

### **Next Steps for Implementing the SDLMI in the Community**

Based on the lessons learned from our pilot work and the key considerations that we identified for planning for person and organization/systems level supports in future research, policy, and practice, our project team has developed next steps for moving this project forward that we hope can be instructive for other support providers, researchers, and policy makers seeking to impact self-determination in community contexts.

### **Integrating Person and System Level Supports**

To effectively deliver SDLMI instruction, facilitators need effective coaching and implementation materials. This is the case whether facilitators are university students, community members, DSPs, or case managers. Ongoing work to explicate and integrate the unique considerations of community-based implementation into training and implementation resources is needed, including the need to plan for communication and to openly discuss with participants with IDD organization and systems-level barriers that might emerge. For example, we plan to integrate more information into the SDLMI Community Facilitator Guide, used by facilitators to guide SDLMI implementation, on how to navigate and communicate with a complex array of support organizations actualizing the advocacy role that is part of being a facilitator but also preparing facilitators to barriers that might emerge. These supports will enhance facilitator's ability to support people with IDD who are creating goals and action plans and may need support from multiple support organizations and may need to engage in self-advocacy to have their goals recognized. We further plan to continue to develop the materials used to implement the SDLMI in community settings and solicit feedback from a broader range of implementers and stakeholders with IDD on how they can be modified and customized to community settings as well as the individualized needs

and goals of participants with IDD in the community. Additionally, we are preparing for remote implementation to meet the needs of adults with IDD to enhance and exercise self-determination during the COVID-19 pandemic.

Further, as noted above, the participants in this project valued the time spent getting to know facilitators and other participants on a personal level; this is a significant benefit of a group-based approach to SDLMI delivery. We anticipated that this would be an important component of the group sessions, however underestimated the time needed both at the start to implement specific relationship building activities through *Finding Me*, but also to allow for time during each SDLMI session to further build trust, connect around activities each week, and build group cohesion. Therefore, in the next iteration of this project, we plan to spend more time using the *Finding Me* guidebook at the beginning of the project, as well as embed more opportunities for relationship development during all sessions. This may be particularly important for adults with IDD who are living in small congregate settings who have more limited opportunities for relationship development and trust building with supporters and facilitators of interventions like the SDLMI (Kozma et al., 2009).

### **Planning for Organization and Systems Level Supports**

Recognizing that people with IDD are supported through a complex array of formal and informal community supports, we also recognize our role as researchers and implementers in conducting contextual analysis to better understand the resources and social capital from which SDLMI implementation can build upon for each participant. By gathering more information about the specific supports utilized by participants, we will better be able facilitate participants' leveraging of community resources to support their goals. This information can be collected through structured conversations with participants, provider organizations, family members, and other members of

support networks. Further, more information about the person's social supports will help us identify and educate "champions" who can support the SDLMI process and advocate with the facilitator and participant to make needed changes to enable SDLMI goals and action plans to move forward.

Additionally, there is a need develop systematic trainings to enhance the knowledge and expectations of paid supports (e.g. DSPs, case managers, job coaches) for self-determination. In our future work, in collaboration with the state developmental disabilities service system, we plan to implement training for these supporters in recognition of the fact that the attitudes and practices of supporters have a great impact on the opportunities and supports needed to exercise self-determination generally and particularly when using the SDLMI. The purpose of the training will be to educate supporters on the importance of self-determination and provide practical strategies that can be used in daily life. This training will also include a planning session to develop procedures within organizations that can be used to communicate with stakeholders who will directly influence the use of SDLMI skills in the community. For example, we learned in our pilot work that we needed to have clear plans to communicate goals set in one domain (i.e., employment), to the job coach and employer; as well as to identify ways to advocate for the case manager to support changes requested by the person with IDD. We will also develop customized administrator training to highlight policy changes that can actualize these changes in supports. Finally, another key aspect to training supporters will be to frame support needs in a strengths-based manner. That is, the presence of extensive support needs (e.g. communication, behavior) does not negate the need and right to exercise self-determination. This requires supporters to support the person's needs to allow for exercising self-determination, and to raise their expectations as well as their understanding of their role as supporters of what is needed for people with IDD to exercise their right to self-determination.

### **Conclusion**

While COVID-19 impacted the degree to which we could collect information on the outcomes of SDLMI implementation in this pilot project, it did allow us to reflect and focus on lessons learned before and after the onset of the pandemic related to the need to change the entire system of support for SDLMI participants to truly enhance self-determination and facilitate person-directed community participation outcomes. The findings from the pilot project suggest that Phase 1 of the SDLMI can be meaningfully implemented with adults with IDD in the community, enabling them to build and express their self-determined goals in areas of their life that are personally valuable to them. However, the project also confirmed the critical need for change across multiple levels to truly enable people to actualize their right to self-determine their own lives. Irrespective of COVID-19, there would have likely been significant barriers to the participants with IDD being able to implement their action plans, without buy-in from their support networks. This highlights the need for education, expectation raising, and creativity to understand the contextual factors that can be either serve as barriers or be leveraged to implement the SDLMI and well as establish the supports and opportunities in the community that enable people with IDD to live self-determined lives consistent with the goals of disability policy.

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Table 1

*Core components and implementation supports of the SDLMI*

Component of SDLMI	Description
Core Components (remain the same regardless of context)	
Person Questions	Each of the three SDLMI phases consists of four Person Questions (12 total). The questions in each phase follow a 4-step problem solving sequence .
Facilitator Objectives	Describes the targeted outcomes for the facilitator in supporting the person to answer each of the Person Questions
Educational Supports	Specific supports that facilitators can use to address the Facilitator Objectives and enable the person to answer the Person Questions
Implementation Supports (tailored to specific contexts)	
Facilitator Training	A standardized, 2-day training by self-determination experts that teach facilitators to deliver the SDLMI
Facilitator Coaching	Ongoing, regular meetings with trained SDLMI implementors designed to enhance implementation of SDLMI
Facilitator Resources	Resources with online modules, power point slides, and sample activities to deliver instruction that meets the Facilitator Objectives and supports the person to answer the Person Questions
Facilitator’s Guide	A guide for SDLMI implementation that supports the facilitator in supporting people to work through the SDLMI, meeting each of the facilitator objectives
Goal Notebooks	Materials that people can use to identify, track, and communicate their goal and progress in responding to each of the Person Questions

Table 2

Participant Demographic Information and Study Information

Participant	Age	Gender	Residential Setting	Number of SDLMI sessions	SDLMI goal area	Race/Ethnicity	Employment Status
Group 1							
1	35	Male	Own Home	16	Enhance Health and Wellness	White	Paid individual job in the community
2	73	Male	Medium-sized Group Home <sup>a</sup>	16	Obtain CIE <sup>b</sup>	White	Paid job in a facility-based setting
3	29	Male	Medium-sized Group Home	12	Obtain CIE	American Indian and White	Paid group job in the community and paid work in a facility based setting
4	33	Male	Medium-sized Group Home	16	Enhance Education	White	No paid job, volunteers in the community
Group 2							
5	29	Male	Own Home	14	Obtain CIE	Black and American Indian	Paid group job in the community
6	61	Female	Medium-sized Group Home	15	Obtain CIE	White	Paid group job in the community and paid work in a facility based setting



7	77	Male	Small Group Home <sup>c</sup>	15	Enhance Health and Wellness	American Indian	No paid job
8	59	Female	Own Home – No Roommate	9	Obtain CIE	White	Paid individual job in the community

<sup>a</sup> Medium-sized Group Home = Setting that includes 4-8 individuals receiving waived services;

<sup>b</sup> CIE = Competitive Integrated Employment

<sup>c</sup> Small Group Home = setting that includes 2-3 individuals receiving waived services;