ADDRESSING DIVERSITY, EQUITY, & INCLUSION: A PROJECT TO ADVANCE SUPPORTED DECISION-MAKING THROUGH COMMUNITY PARTNERSHIPS

**Pursuant to a grant from the
Massachusetts Developmental Disabilities Council**

FINAL REPORT

July 31, 2024

CPR Center for Public Representation

PROJECT SUMMARY

The Center for Public Representation (CPR), in collaboration with key community partners, and the financial support of the Massachusetts Developmental Disabilities Council (MDDC), designed and implemented an innovative "gap-filling" initiative to make Supported Decision-Making (SDM) more available to linguistically, ethnically, and culturally diverse communities in Massachusetts. CPR partnered with community leaders and advocacy organizations to pilot trainings on SDM and other alternatives to guardianship that were specifically designed for and vetted by family members of people with intellectual and/or developmental disabilities (IDD) within underrepresented and underserved populations.[1] We intentionally embedded this project within CPR's Racial Equity Initiative (REI) with the goal of reaching people who historically have not received accessible and culturally responsive information about SDM. The lessons we learned as an organization because of this project, coupled with the meaningful partnerships we fostered and deepened with community organizations, including Conexiones Latinx-MA (CLMA) and the Black Autism Coalition, among others, will continue to inform our broader work to bolster the use and acceptance of SDM not only in Massachusetts, but across the country.

CPR AND THE STAFF WHO WORKED ON THIS PROJECT

For almost 5 decades, CPR has fought to advance and enforce the rights of people with disabilities using diverse legal strategies, systemic reform initiatives, and policy advocacy. Our work centers upon enforcing the civil rights of people with disabilities, expanding their opportunities for inclusion and full community participation, and supporting their ability to exercise choice in all aspects of their lives. CPR has a long history of contesting guardianship in court and working to promote guardianship reform in Massachusetts and nationally. Indeed, ensuring that people with disabilities can exercise self-determination and have opportunities to make meaningful decisions that shape the trajectory of their lives has been a seminal part of CPR's advocacy since its inception.

CPR is a national and international leader in advancing Supported Decision-Making (SDM), through pilots, training, and technical assistance. In 2014, CPR partnered with Nonotuck Resource Associates in Massachusetts to launch the nation's first externally evaluated SDM pilot, which demonstrated that SDM is a viable alternative to guardianship and improves people's lives. As part of that pilot, CPR successfully represented the first Massachusetts resident – a person with IDD – in terminating his guardianship in favor of SDM. In 2018, CPR developed an SDM incubator model to help five Massachusetts organizations, including the Multi-Cultural Center in Springfield, launch their own pilots. CPR also partnered with the Georgia Developmental Disability Council and the Georgia Advocacy Office (Georgia's Protection & Advocacy Agency) on an SDM pilot linked to the Citizen Advocacy human rights movement. The lessons learned from these pilots resulted in a CPR co-authored article that informed the deliberations of the Fourth National Guardianship Summit. CPR also established an SDM Training and Technical Assistance Center, including a virtual resource library accessible through our website, https://supporteddecision.org. CPR provides technical assistance to advocates on these issues in Massachusetts and across the country. For example, over the last four years, CPR has been a key partner of the Center on Youth Voice, Youth Choice (CYVYC), a

---

[1] There were other elements of the grant that we received from MDDC, including providing technical assistance to MDDC's peer training program in its efforts to develop an SDM training program for people with IDD. This report is a separate deliverable under this grant and focuses on the lessons learned from piloting the SDM family training module to promote future replication of such trainings.

national resource center that advances alternatives to guardianship for youth with IDD. Through CYVYC, CPR provides technical assistance to eleven State Teams across the country.

CPR is committed to continually working to ensure our legal advocacy and initiatives, including our SDM work, not only amplifies the voices and leadership of people with disabilities, but is centered on the needs of those most marginalized within the disability community. CPR has developed, piloted, and refined a Racial Equity Assessment Tool for initiatives, which was designed to promote equitable access and outcomes through the intentional inclusion of people from underserved and underrepresented communities. It prompts us to carefully consider team composition, allies and trusted partners, and impact on marginalized and diverse groups of people before we undertake an initiative, with an emphasis on identifying the bias and structural racism that could impact communities of color. We have long identified the need to focus our SDM work on reaching racially, culturally, and linguistically diverse communities, and this project afforded us an opportunity to undertake this work in an intentional and meaningful way, with the invaluable support of community leaders and innovators.

This project was undertaken under the direction and leadership of Cathy Costanzo, CPR's Executive Director. Project staff included Morgan K. Whitlatch, Director of SDM Initiatives; Mona Igram, Director of the Racial Equity Initiative; Megan Rusciano, Staff Attorney and member of the SDM Initiatives team; Michael Kendrick, former Senior Advisor on SDM; and Lila Shane, Director of Finance and Operations. For more information on CPR's SDM Initiatives team, visit: https://supporteddecisions.org/center-for-public-representations-sdm-work/staff/.

STATEMENT OF NEED

Self-determination is a foundational piece of human identity. The notion that, as human beings, we can make the decisions that allow us to chart the course of our own lives, is a critical part of how we see ourselves and move through the world. Nonetheless, when a person is thought not to have the ability to make decisions, someone else may be empowered by some action of law to act for that person as a substitute decision-maker, often through guardianship. People who are subject to plenary guardianship (estimated at more than 1.3 million nationwide)[2] have little to no rights to make their own decisions about their personal health care, their finances, whether to marry and raise a family, with whom to associate, and other day-to-day decisions others take for granted. National Core Indicator data suggests guardianship is overused for people with IDD in Massachusetts, with 47% of people receiving publicly funded developmental disability services under full or plenary guardianship, compared to the national average of 28%.[3]

For years, advocates in the medical, legal, and disability rights fields in Massachusetts have been promoting less restrictive alternatives, such as healthcare proxies, advanced directives, durable powers of attorney, and SDM – but guardianship continues to be the default, particularly for youth with IDD approaching adulthood. It is understandable that families want to ensure the safety of loved ones with disabilities, but there are options other than guardianship that can provide protection without ceding choice. Decisional supports, such as a healthcare proxy, an advanced directive, or money management support, can allow people to retain their rights and their independence. SDM enables individuals to work with a team of chosen supporters to make life decisions. It is the option that most respects the person's voice and honors the person's choice. Decades of research have shown that people with disabilities who are

---

[2] NAT'L CTR. FOR STATE CTS., *Brief No. 7: Data Quality Undermines Accountability in Conservatorship Cases*, , at 5 (2018), https://www.eldersandcourts.org/__data/assets/pdf_file/0021/5844/ovc-brief-7.pdf.
[3] NATIONAL CORE INDICATOR, CHART GENERATOR 2017-2018, http://www.nationalcoreindicators.org/charts/.

supported to have greater control over their lives have better life outcomes, are more integrated into their communities, are healthier, and are more able to resist and avoid abuse.[4]

As a result of CPR's experience with SDM initiatives, we know that more is needed than statutory or court reform to successfully improve access to SDM. An initiative cannot change the tide towards alternatives to guardianship, including SDM, without robust community education and buy-in. Yet, too frequently, families supporting people with IDD are not given the information that they need to understand that less-restrictive options are available and might be more appropriate. Systemic training initiatives must be developed and implemented that provide families with information about the full array of decisional supports for people with IDD before they get to the courthouse door.

An initiative cannot change the tide towards alternatives to guardianship, including SDM, without robust community education and buy-in.

While there is a need for these systemic training initiatives, we also know that several initiatives thus far have failed to significantly reach linguistically, ethnically, and culturally diverse communities in Massachusetts and across the country. In Massachusetts, there are few resources on SDM that are specifically tailored to non-English speaking or limited English proficient communities. Yet the need is there. Over the last decade, the Latinx population has had the most growth in Massachusetts, increasing by over 40% between 2010 and 2021.[5] The top languages other than English that are used in Massachusetts are Spanish, Portuguese, Chinese (including Mandarin and Cantonese), Haitian, French, and Vietnamese. We also know from our experience with linguistically diverse communities as part of our SDM pilots and the CYVYC project, that more is required than mere technical or simultaneous translation of SDM training materials to make them accessible to non-English speaking communities. Guardianship as it operates in Massachusetts, and the United States as a whole, is a Western construct requiring culturally competent and tailored explanations. Studies have shown there are myriad differences in how notions of self-determination itself manifest across cultural groups.[6] There is also a need to tailor educational resources about SDM to the experiences of other marginalized communities, including the LGBTQIA+ community, who experience unique barriers to inclusion and challenges to their decision-making.

Resources geared towards these communities must be created and disseminated through a thoughtful and intentional process that is mindful of the need to respect, acknowledge, and celebrate these differences. Our project was designed to find an innovative way to create these resources through a framework that can be replicated not only in Massachusetts, but also across the country.

---

[4] *See* NATIONAL COUNCIL ON DISABILITY, *Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination* (2018), https://www.ncd.gov/assets/uploads/docs/ncd-guardianship-report-accessible.pdf, at 132 and n. 332 (citing research studies on the impact of self-determination on people with intellectual and developmental disabilities).

[5] *See* U.S. Census Bureau, *Massachusetts Profile,* https://data.census.gov/profile/Massachusetts ?g=040XX00US25.

[6] *See* Tawara D. Goode, *Self-Determination: Cultural Differences in Perception and Practice,* 32 IMPACT 1 (2019), https://publications.ici.umn.edu/impact/32-1/self-determination-cultural-differences-in-perception-and-practice. *See also* Phil Smith & Christie Routel, *Transition Failure: The Cultural Bias of Self-Determination and the Journey to Adulthood for People with Disabilities*, 1 DIS. STUDIES QUARTERLY 30 (2010), https://dsq-sds.org/index.php/dsq/article/view/1012/1224.

IMPLEMENTATION OF THE PROJECT

Establishing an Advisory Committee and Using a Racial Equity Assessment Tool

We decided to use CPR's Racial Equity Assessment (REA) tool to guide us through this process. The CPR REA tool explicitly prompts consideration of the impact of our projects on marginalized, underrepresented, and linguistically diverse communities, with an emphasis on identifying the bias and structural racism that could have an impact on communities of color. The tool sets out seven major categories for consideration: identifying the purpose, identifying the team, assessing disparities using data, reviewing and analyzing engagement and accountability, assessing systems change, avoiding adverse impacts, and furthering racial equity objectives.

In using this tool to assess the project team, team resources, and data disparities, we had to think "outside the box." We initially looked to various publicly available data sources to determine which communities were underrepresented in terms of access to SDM. We reviewed data associated with guardianship petitions filed in Massachusetts probate court, MDCC annual reports, National Core Indicators of publicly funded developmental disabilities systems, Commission on the Status of Persons with Disabilities, and the Massachusetts special education system. The data collected was most often not disaggregated by race, ethnicity, and/or age. For example, although Massachusetts courts keep data on the number of guardianship petitions that are filed, they do not include race, ethnicity, or age data in their metrics.

To broaden the perspectives of our team, as well as gain access to qualitative data, CPR formed an SDM Project Advisory Committee, which focused on principles of anti-racism, cultural responsiveness/humility, and intersectionality in providing input, feedback, and evaluation of this project. We invited people who were interested in SDM and came from a variety of professional, racial, and ethnic backgrounds, as well as those with lived experience of guardianship or SDM, to partner with us in the development of the training curriculum and our outreach planning. The group included people with disabilities, people with multiple linguistic capacities, attorneys, and community advocates. We made contact personally with invitees who we thought might be interested and added critical perspectives to our discussions. We sent a follow-up letter describing the project and the goals of the committee, including the primary purpose of providing underrepresented communities with "culturally competent resources and training that will help support individuals with disabilities to make their own choices about their own lives." We committed to providing mutual support to Advisory Committee members by finding ways to amplify their work, since they were generously offering us their time and expertise.

> *To broaden the perspectives of our team, CPR formed an SDM Project Advisory Committee, which focused on principles of anti-racism, cultural responsiveness/humility, and intersectionality in providing input, feedback, and evaluation of this project.*

During the course of this year-long project, the Advisory Committee met four times. We asked the Advisory Committee to weigh in on our approach to prioritize community needs, provide statewide support to the project, and review and comment on the training curriculum and content. The Advisory Committee provided critical insights and guidance that shaped how we conducted outreach, developed the training module, and identified the next steps. It also served

as a gateway to the communities we were eager to reach. As a result of the invaluable input we received from the Advisory Committee, we have asked the Committee to continue to meet two or three times a year to inform our SDM work moving forward.

Some of the critical feedback we received from the Advisory Committee included the following:

- Families of people with IDD frequently are under the impression that they have only one option when it comes to providing support with decision-making in adulthood – namely guardianship. More accessible and culturally competent educational materials are needed.

- Meeting communities where they are is essential to effective training. It is also critical to see educational material and training as the beginning of a larger and longer conversation. It is important to give people the time, space, and respect they need and deserve to digest information and make an informed decision.

- Operationalizing outreach must be local in each community, given whatever resources the community has available, and consistent interactions and relationship-building with families are critical.

- Building trust with underrepresented communities by including community leaders and community members with lived experience in planning, outreach, and training, and by fostering mutually supportive and beneficial relationships is essential.

- The approach towards education and training needs to be one with a clear "lack of judgment" toward families who are trying to navigate significant amounts of information and fears surrounding guardianship and its alternatives.

"Folks think they have only one option (guardianship); having materials that will be easily read, understood and translated correctly…will help to better serve the community."

- Strategic use of videos in trainings, as well as visual resources with QR codes and social media outreach strategies, encourages easy access to needed information.

- Educational materials should be available to families early on and well before a child turns 18 years old.

- Materials should be provided in concert with other agencies to ensure consistent messaging.

- In addition to families, third parties, including medical professionals and IDD service agencies, need to be educated about SDM and alternatives.

We also received feedback on our work from MDDC's Diversity, Equity, and Inclusion (DEI) Committee, which is comprised of professionals and people with disabilities and their families. CPR staff provided an overview of the project, approach, and our findings. We learned that members of the DEI Committee saw our work and this curriculum to be "so critical" and in need of continuation, because "families aren't going to learn by one session." The group also

recommended developing a train-the-trainer model, where we could provide education and resources to community leaders, who could in turn train families within their communities.

The feedback from the Advisory Committee and the MDDC's DEI Committee proved vital to the development of the training module curriculum and toolkit and will inform our work in this area going forward.

Convening Focus Groups

The objective of this project was to work with partners to pilot and evaluate culturally competent training modules on SDM and other alternatives to guardianship for family members of people with IDD from diverse communities in Massachusetts. We focused this educational initiative primarily on family members of transition-age youth and young adults, ages 14 to 27, with IDD.

While CPR staff have trained a variety of audiences in Massachusetts and nationwide on SDM and other alternatives to guardianship, we adopted an intentional approach to receiving input from the impacted communities we were seeking to reach. We held two focus groups, one in English (with interpretation available upon request) and another in Spanish to determine how to approach the content of the training. Some of the most informative and powerful lessons we learned throughout this project came from these focus groups, where we learned directly from family members of people with IDD what their concerns about guardianship and its alternatives were and what approaches to sharing information about these topics would be most effective within their communities. The invaluable insights and perspectives shared by the participants in the focus groups helped us meaningfully calibrate our curriculum to the audience.

Critical partners in organizing these focus groups included Keila Torres, who is the Executive Director of Conexiones Latinx-MA (CLMA), a community leader, bilingual advocate, trainer, mother, supporter, and guardian of family members with IDD, and Fatima Baptista, MDDC Public Health

"Thank you very much for giving me the opportunity to express myself freely."

Community Engagement Specialist, Assistant Director of the South Coastal Family Support Center, and facilitator of a community group called Sawubona. Together we strategized around community messaging and developed flyers to recruit participants and a list of questions to guide the focus group conversations. The questions included asking what people knew about guardianship and SDM, what and how they wanted to learn, and what they believed parents needed to know about these topics. Ms. Baptista helped recruit five participants for the English focus group from Sawubona, and Ms. Torres helped recruit five participants for the Spanish focus group from her CLMA network. Our partners' willingness to actively recruit participants from their communities helped build trust towards both CPR and our training initiative. All participants in the focus groups were offered a stipend for sharing their insights with us, both to recognize the value of their expertise, input, and time, and to reinforce an environment of respect.

To identify interpreters for both the focus groups and trainings, we asked for recommendations from our community partners, namely a transition specialist from Lawrence High School who served on our Advisory Committee. She recommended an interpreter who regularly worked with families in these communities and was mindful of the linguistic differences within the Spanish-speaking community when translating and interpreting. We also asked our partners whether CPR staff should attend the focus groups or whether our presence would chill the

conversation and dissuade families from freely sharing their feedback. Our partners indicated that this was an important question to ask, but that they did not believe our presence would inhibit discussion. Based on the feedback from focus group participants, our efforts to work with our partners to create a welcoming environment were successful. As one participant said, "Muchas gracias por darme la oportunidad de expresarme libremente." (English translation: "Thank you very much for giving me the opportunity to express myself freely.")

Participants in the focus groups made a number of critical reflections:

- In some cultures and countries, "you never go through [the guardianship] process there," so the concept of guardianship is new to some families.

- Not all families understand what guardianship is and what its consequences are. For example, one participant thought guardianship "is not a legal process. It's just paperwork." Another wanted families to understand what she

    "Hearing someone right now say there are cons to guardianship, I never thought about that before…and I wish people would talk about that, because no one's even said it before."

    was not told before getting guardianship – that it meant she could not serve as paid staff for her child under DDS' system of home and community-based services. Another participant shared that "hearing someone right now say there are cons to guardianship, I never thought about that before…and I wish people would talk about that, because no one's even said it before."

- Families want to hear information shared from people with lived experience, including people with disabilities and families. As a participant shared, information is more compelling "when the person is going through the same thing that you're going through or went through." Adding to this point, a participant said that, in considering guardianship and alternatives, "you're in that moment of unknowing, of fear, of worrying," and hearing the perspective of someone who "has already gone through that stage" helps.

- Different modalities of presentations, including videos, tips sheets, and guides as to what steps to take as children reach certain ages are helpful to families.

- For Spanish-speaking families, more resources in their language are critical. Many participants added there "aren't a lot of resources in Spanish for us parents." Another added that the available information about guardianship and its alternatives is not accessible or easy for families to read.

- Information must be culturally competent, recognizing the cultural differences within the community. Participants remarked that Latinx families are close-knit and that many families stay and live together across generations. As a result, suggesting that a child should consider moving to a residential placement when they become an adult or presenting information through a lens of rights and independence may not resonate. One participant added, "I can just say from my own culture…that, you know, once you're my child, you're my child forever. And I make decisions for you with or without a Judge telling me to. And I think that's [a] very hard and a sensitive topic for many families."

- The terminology around guardianship is confusing. Families are used to being the guardian of their child, but when the child turns 18 years old, they may not know that legally "guardianship" means something different.

- Educating through practical examples about how alternatives to guardianship work is important. For example, a participant told a story about what helped her change her mind about putting her son in an inclusive classroom. She had heard people say "inclusion is important" and generally supported inclusive classrooms, but she was not convinced that it would be safe for her son, because he had communication access needs. She then heard

> *"Very happy and satisfied with the initiative to gather the Hispanic family community with a moderator who knows the language and culture."*

a story from a mother whose child also had communication access needs, was in an inclusive classroom, and was inappropriately restrained. The students without disabilities in the classroom saw the restraint and spoke up to defend their peer. Hearing this story made the focus group participant realize that her child was not necessarily safer in a segregated classroom. As she said, "the point of the story was inclusion protects your children. You think they're going to be protected if you isolate them, but it's not true. The more they're included, the more they're around others, the more they're incorporated … that's going to protect your child." It was that practical story, and not esoteric education about the importance of inclusion, that changed her mind about what would be best for her child.

- Providing examples of how SDM works for people with disabilities who have more support needs than others, including those related to communication access, would be helpful for some families. Otherwise, families of people with more support needs may not see SDM as an option or relevant to their particular situation.

- Feedback on the focus group experience of the participating family members was uniformly positive. For example, one participant reflected that she was "very happy and satisfied with the initiative to gather the Hispanic family community with a moderator who knows the language and culture." Another had "high hopes that good will come out of this discussion." The feedback also spoke to the strong need for this SDM work and community conversations to continue.

The focus groups provided us with invaluable guidance for how we would approach developing not only this SDM curriculum, but future ones.

Pilot Trainings with CLMA and The Arc of Greater Haverhill-Newburyport (GHN)

We partnered with CLMA and the Arc of GHN on one training pilot designed to reach Latinx and other underrepresented communities. The trainings took the form of webinars, one presented in Spanish and one presented in English (with translation available upon request). A webinar – rather than an in-person training – was recommended by not only CLMA and The Arc of GHN, but also an Advisory Committee member who worked regularly with the Latinx community in supporting transition-aged youth with disabilities, given their experiences with the preferences of family members. After the focus groups, CPR and CMLA met to discuss how we could

incorporate the lessons learned into our training materials. Identified elements that were critical to include in the SDM training module included the following:

- Families are frequently not aware that there are other options aside from guardianship. We should approach the conversation about guardianship and its alternatives as a fully respectful one that is designed to ensure families are aware of all of their options, so they can make an informed choice with their child. We used this lens in framing the training material, rather than centering the conversation around "rights" or "access to independence," which focus group participants indicated would not be useful frameworks to reach families in some of these communities.

- Families may not know that guardianship is a formal legal process involving ongoing involvement with the court. The presentation should explain the consequences of guardianship as a legal construct.

- Families may not know that there are downsides to guardianship. Training content should describe what guardianship is, what it is not, and what its potential drawbacks may be.

- Families may not understand how being a guardian of a child is different from adult guardianship. The training should make that distinction, so families understand how, under Massachusetts law, their legal relationship with their child changes when that child turns 18.

> *Omar said that not having a say in decisions would feel "like I don't have a voice . . . like . . . I have these invisible shackles around my neck."*

- Hearing from people with lived experience is important. Therefore, it is essential to include people with IDD and their family members as presenters and experts within trainings. For example, we developed videos (one in English and one in Spanish) with Ms. Torres' son, Josué "Omar" Torres, who identifies as a person with IDD and was willing to share his journey with SDM and self-determination. We compensated him for his time, and he shared some powerful insights:
    o Mr. Torres spoke about using SDM with his parents and that he enjoyed "that special connection . . . and knowing that they are going to be there for [him]".
    o He added that not having any say about decisions in his life would feel "like [I] don't have a voice . . . like . . . I have these invisible shackles around my neck and no matter how hard I tried it just won't budge."
    o He talked about the impact of being underestimated and how he has worked with his family to overcome low expectations. "I've always struggled with self-confidence, but in moments where I needed it most, I was able to get my head straight and push forward and I've been able to accomplish things that I never knew were possible."

- Families may not understand how guardianship does not necessarily make people safe. Addressing families' concerns about safety in this SDM training initiative is important. For example, we discussed how guardianship does not automatically prevent people with IDD from being hurt and how self-determination can help protect people with IDD against abuse and neglect.

In the end, our training module curriculum and toolkit included a PowerPoint presentation, Mr. Torres' videos about his journey with SDM, and a handout that included resources and links to relevant forms for alternatives to guardianship. All materials were provided in English and Spanish. We also developed short flyers (in English and Spanish) with QR codes that linked to English and Spanish training information and resources on CPR's SDM website. All of these materials are available on https://supporteddecisions.org.

"Excellent training . . . Keila's presentation and Omar's interview gave the important point of view from people who practice supported decision-making."

With the help of Rowan DeAza, a Bilingual Family Supports Navigator from The Arc of GHN, we developed flyers, in English and Spanish, to advertise the training through a variety of community networks, including those of CLMA, The Arc of GHN, DDS, Family Support Centers, Family Resource Centers, and other diversity, equity, and inclusion partners. We framed the training in a way that recognized CLMA's critical subject matter expertise. Both webinars were well-received by the vast majority of participants who provided feedback, with some referring to the presentation as "excellent" and appreciating "the links provided for reference and Spanish-speaking resources."

Other Trainings

Through our work on this project, we heard from our partners that there are many other communities that need culturally, linguistically, and ethnically responsive materials about SDM. From these conversations, we identified the need both to expand our work with the Latinx community and to approach and reach other communities. We connected with partners, including the Black Autism Coalition, Parent/Professional Advocacy League (PPAL), Northeast Arc and NAGLY, The Arc of Massachusetts, the Monorom Family Support Program of the Cambodian Mutual Assistance Association (CMAA) and others to collaborate on trainings about SDM

"I really liked Leonard's perspective. It made me think of my daughter and how she would like to be treated/supported."

that embrace our model of co-collaborating to develop content and co-presenting with community partners and people with lived experience. For example:

- Black Autism Coalition (BAC) **–** We partnered with BAC to make an SDM training culturally competent and accessible for a Haitian Creole community. This involved planning meetings with Cynthia Laine – BAC Executive Director, community leader, advocate, mother, and Haitian Creole interpreter – to understand what format and approach would best resonate with the audience. As a result, this SDM session was: (1) framed around a series of introductory questions about SDM and other alternatives to guardianship, rather than involving a lecture or PowerPoint presentation; (2) streamed on social media via Facebook Live, rather than being within a webinar; and (3) facilitated – not just interpreted – by BAC and Autism 509 through a back-and-forth style conversation with CPR staff. Because it is critical to recognize the expertise of people with disabilities when it comes to SDM, BAC invited Gyasi Burks-Abbott, citizen member of the MDDC Board and self-advocate with IDD to present at a Facebook Live session a

week before our presentation. Flyers were used on social media and email to advertise the training. The SDM session was well-received, with one participant commenting: "Thank you so much . . . We have learned so much." A recording of the session was posted to YouTube and is available at https://supporteddecisions.org.

- Parent/Professional Advocacy League (PPAL) – We partnered with PPAL to schedule an additional training for parents of youth with IDD who are dually diagnosed with mental health disabilities. To do so, we met with PPAL staff, including family members of people with those disabilities, to refine the curriculum and training materials. We also presented alongside Leonard Stevens, a person of color who has both IDD and a mental health disability, who shared his experience using SDM. The presentation was well-received, with participants describing the information provided as "very practical" and "relevant." A number of them highlighted the importance of hearing Mr. Steven's story, with one participant stating: "I really liked Leonard's perspective. It made me think of my daughter and how she would like to be treated/supported."

LESSONS LEARNED AND PROMISING PRACTICES

As an undertaking, this project illustrates ways to rethink education and outreach initiatives on SDM and other alternatives to guardianship through an equity lens. Below we have highlighted critical lessons learned and promising practices that we took away from this work.

In terms of broader lessons that we learned through this project:

- Families are truly excited by and eager to learn more about SDM and other alternatives to guardianship. There is both a deep appetite and need for this information in Massachusetts, and educational initiatives like this one should continue.

- While we were able to create a cadre of new resources for families through this initiative, there is still a huge gap in accessible resources on SDM and other alternatives to guardianship for diverse communities. More resources need to be developed that recognize a broad variety of linguistic and cultural differences.

  The most compelling and impactful stories about SDM and other alternatives to guardianship come from people with disabilities and families.

- Education initiatives that extend beyond family members of people with IDD are also needed. Third parties, such as medical professionals, schools, courts, and State developmental disabilities (DD) agencies and providers need to receive ongoing education and training on SDM and other alternatives to guardianship. Without this education, they will provide families with inconsistent -- or worse, incorrect -- information about what their options are.

- As we suspected, the most compelling and impactful stories about the importance of SDM and other alternatives to guardianship come from people with disabilities and their families. People with this lived experience should be recognized as the experts in these education and training initiatives and compensated for their work and time accordingly.

- Additional funding is needed to support initiatives that can develop and propel real partnerships around SDM and other alternatives to guardianship that are aimed at reaching and training families within marginalized communities. Community leaders, including family and peer-driven advocacy groups within underserved communities, should receive additional financial support and recognition to expand the work that they already do and the dynamic partnerships that they help to foster.

- This project should be seen as only the beginning. We have more to learn and are eager to find ways to expand this work to make SDM and other alternatives to guardianship more accessible to underserved and underrepresented communities.

In terms of specific promising practices for future training initiatives like this one:

- Creating an Advisory Committee of community leaders, experts, and people with lived experience is a helpful way to meaningfully inform, guide, and shape an initiative through the lenses of race, diversity, and equity. When inviting community partners to the table, adopt an approach that ensures mutually beneficial relationships that amplify all collaborators' work and growth.

> *This project should be seen as only the beginning. We have more to learn and are eager to find ways to expand this work.*

- Building flexibility in terms of the format of educational sessions is key. Different approaches – formal webinars, in-person training events or conferences, social media events, or more informal discussion opportunities – may resonate and be more effective with different communities. Be open to implementing different modalities.

- Convening focus groups and planning sessions with individuals from impacted communities is a way to ensure that a training curriculum's structure, content, and approach are relevant and responsive to their wants, needs, and experiences. Community partners may be willing to assist in recruiting participants for focus groups and can provide vital feedback on how to make the discussion accessible, welcoming, and productive. Focus group participants should be compensated for their time and expertise.

- If interpreters or translators are needed as part of an initiative, solicit recommendations from community partners who are familiar with the quality and effectiveness of their services in practice and who know the preferences of the intended audience. Screening interpreters based on their familiarity with linguistic and cultural differences within a particular language should also be considered. In terms of the form of interpretation, recognize that presenting in English with simultaneous interpretation is not as accessible as presenting in the audience's preferred language.

- Develop training materials and presentations in partnership with members of the targeted community, who are the true authors and leaders of this work. Always include people with lived experience as subject matter experts within trainings and presentations. In our experience, hearing from other family members and people with disabilities is the most effective way of helping audiences understand the value and importance of SDM and other alternatives to guardianship.

MOVING FORWARD & NEXT STEPS

While the term of this grant has come to an end, we have identified a number of next steps moving forward, both in the short and long term. Some are already planned or underway, and others represent ideas for future projects and fundraising efforts.
Short-term next steps include the following:

- We are using this project's model and promising practices for promoting community engagement in a partnership with the Monoram Family Support Program of the Cambodian Mutual Assistance Association (CMAA). We are collaborating with CMAA to develop a training on SDM and other alternatives to guardianship for families from the Cambodian community in Lowell, Massachusetts. We will thus be expanding available resources on SDM to another cultural and linguistic community in the state. Based on feedback from CMAA, we already know that the format, approach, and materials will look quite different from what we implemented during this grant period.

- We are exploring other avenues for SDM training pilots tailored to: (1) the LGBTQI+ community, in partnership with the Northeast Arc and North Shore Alliance of GLBTQ Youth (NAGLY); (2) other linguistic and cultural communities, in partnership with The Arc of Massachusetts; and (3) family forums with judges and court personnel.

- We are exploring ways in which to continue convening our Advisory Committee beyond the grant term. Members have expressed interest in continuing to advise us on our SDM work. We, in turn, are committed to finding ways to continue to partner and support the work of not only Advisory Committee members, but also all the organizations we partnered with during the course of this project.

Longer-term considerations for future initiatives, based on the recommendations of the Advisory Committee, focus group, and other partners, include the following:

- Expand and deepen family and peer advocacy groups' knowledge about the importance of alternatives to guardianship, including SDM. Educating community leaders can help create a train-the-trainer model that can effectively reach more members of underserved communities. Educate families on the available options early on in their child's life.

- Develop and convene legal clinics that allow families to receive information and advice on SDM and other alternatives to guardianship when they need it -- including one-to-one support – to improve access.

- Implement more training initiatives tailored to additional audiences, including state agencies and service providers; medical professionals, pediatricians, and community health center staff; court service centers; and judicial and court personnel.

- Continue to promote the enactment of legislation in Massachusetts that would formally recognize SDM. While it is not required for people to use SDM, such legislation may be helpful in persuading courts and third parties to recognize and respect it.

ACKNOWLEDGMENTS

This project would not have been possible without the financial support of MDDC. We would also like to provide special acknowledgments to our invaluable partners who made this project possible: Keila Torres and Conexiones Latinx-MA; Rowan DeAza and The Arc of Greater Haverhill-Newburyport; Cynthia Laine and the Black Autism Coalition; Yveline Alexandre and Autism 509; Meri Viano, Pamela Bows, and PPAL; Fatima Baptista; Gyasi Burks-Abbott; Sabrina Mayor; Leonard Stevens; Omar Torres; and our Advisory Committee members not already named: Virginia Benzan, Melody Cooper, Elaine Davey, Jevon Okundaye, Noel Sanders, Laura Sanford, Diana Santiago, and Tanasia White.

CPR thanks MDDC for its support of this work and all the partners who helped ensure the success of this project. We believe that we have produced a framework that can be replicated in other communities and that fills a critical gap in resources about SDM.