

# SUPPORTED DECISION-MAKING: ADDRESSING DIVERSITY, EQUITY, & INCLUSION

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# WHO WE ARE

**GEORGIA ADVOCACY OFFICE** is the Independent, Federally Mandated Protection and Advocacy System for People with Disabilities in Georgia.

**I DECIDE GEORGIA** is a coalition of advocates, organizations, and allies who believe in the dignity of every person.

**CENTER FOR PUBLIC REPRESENTATION** is a national legal advocacy center for people with disabilities that uses legal strategies, advocacy, and policy to promote integration and full community participation.

# SUPPORTED DECISION- MAKING: ADDRESSING DIVERSITY, EQUITY, & INCLUSION

- Explore the practice of Supported Decision-Making (SDM) as a person-centered and culturally responsive strategy for overcoming intersectional barriers people with disabilities face when seeking decision-making supports.
- Highlight lessons learned in Georgia and Massachusetts projects seeking to increase access to SDM in underrepresented and underserved communities

1

Replicate and refine key strategies for using SDM to overcome intersectional barriers people with disabilities face in decision-making

2

Identify and understand promising practices for making SDM more available to linguistically, ethnically, and culturally diverse communities

3

Understand ways to cultivate and support the leadership of people with lived experience in SDM initiatives

## LEARNING OBJECTIVES

Person-centered thinking (PCT) is a philosophy that prioritizes individuals and helps them lead fulfilling, independent lives. It's based on a set of principles and core competencies that include:

**Respect:** Treating others with dignity and respect

**Informed choice:** Recognizing the right of individuals to make informed choices

**Self-direction:** Supporting people's positive control and self-direction of their own lives

**Strengths:** Building on the strengths, gifts, talents, skills, and contributions of the individual

## WHAT IS PERSON CENTERED THINKING?





Cultural competence is the ability to communicate with and interact with people from different cultures. It's a lifelong process that involves being open, flexible, humble, and sensitive to others.



It is an awareness of how cultural perspective influences judgement about what is deemed to be 'appropriate', 'normal', or 'superior' behaviors, values, and communication styles.



Cultural Competence also requires an understanding of the impact of social context on the lives of culturally diverse populations, and how power, privilege, and social oppression influence their lives.

## WHAT IS CULTURAL COMPETENCE?

# PEOPLE W/DISABILITIES FACE MANY BARRIERS TO DECISION MAKING SUPPORT

## Cultural

- Beliefs about causes of disability
- Social Structure in culture
- Age or Family roles

## Impact of Disability

- Binary thoughts about capacity

## Linguistic Capabilities

- People who do not rely on speech alone
- People whose primary language is not English

# BARRIERS CONTINUED...

## Economics/Class

- School support
- Technology
- Legal services

## Citizenship Status

- Access to courts
- Fear of government intervention

## Gender Identity or Sexuality

- Non-traditional support
- Decisions are not trusted seen as valid



- Valued community roles or employment opportunities
- Perceived as religiously superior or closer to God
- Included and integrated with full rights as citizens
- Caused by disease or biological dysfunction
- Inclusion is hoped for but not required
- People with disabilities are experts in their own experience

- Limited or no community roles or employment opportunities
- Perceived as religiously inferior or influenced by evil
- Isolated and segregated with restricted rights as citizens
- Caused by human actions or ancestral sin
- Cause of fear, shame and stigma
- Doctors are experts and have authority that should be obeyed  
Everyone has an opinion or claims to be an expert

## Cultural Views On Disability Vary Widely



SUPPORTED  
DECISION-MAKING  
IS A FLEXIBLE  
PERSON-CENTERED  
TOOL

# The SDM CHAMPION



The person supporting the process

- Must be chosen by the person\*
- Must be committed
- Must be able to engage and teach others
- Must be creative and willing to try another way
- Must know the person really well, understand their communication, able to distinguish between true yes and no/interest and disinterest
- Familiarize yourself with the process, it won't happen all at once but look for and use every opportunity to offer choice and control.



- Where do you want more choice and control?
- What goals do you have?
- What about (work, home, relationships, health, money management, spirituality, community involvement)
- Do you want more friends? Do you want more choices about your free time?
- What's important to you in your life? What could be better? What don't you like about your life?



# DECIDE NLIST

- Who listens to you?
- Who is good at helping with (what ever the goal is)?
- Who helps you do the things you want to do?
- Who can you talk to about hard things?
- Who responds to you, answers or comes when you ask?
- Who wants you to have a good life?
- Make suggestions and double check



# DECIDE HOOSE

- How do you learn best; do you want to hear, see, read, try, watch others?
- How do you want to be supported to make decisions; one on one, in a group with trusted people, send emails with questions, discuss in person?
- What choices and decisions are you already good at making? How did you learn that?



# DECIDE INFORM

- Who do you want to respect your decisions?
- Who needs to know about this process?
  - Doctors, teachers, banks, service providers
- Do you want to use a document
  - SDM Agreement
  - Release of Information
  - Power of Attorney
  - Advance Directive
  - Psychiatric Advance Directive



**DECIDE**

**ETERMINE**



- How will we know we are meeting your goals?
- How will we know you are learning these skills?
- How will we know this is working the way you want it to work?





# DECIDE

# EXPERIENCE

- What opportunities do you need/want to practice?
- When can/should that happen? How often?
- What does practicing look like? What happens when you make a mistake?
- What happens when what you want is different from what others want?
- How do we make sure you stay safe will learning (safe failing, guardrails)?



In different places its harder for people to get support. One of the big reasons is culture. Culture effects how someone understands their problems, how to seek help, how it affects them socially, and even how they cope with it.

As a first-generation kid, it was hard. The Virgin Islands is quite behind when it comes to social awareness or acceptance, so my mom and I had no clue what to do when we learned I had autism. We didn't know what I was going to do in the future.

There were things I struggled with. I never wanted to make eye contact, did what to be at the carnivals or parties and I hated traveling. I did not want to fit into normal girl standards, something that the Virgin Islands was not keen on.

Making my own decisions as a person with autism was frustrating . I didn't know the right words and making choices was hard when the culture didn't favor my opinion

I DECIDE gave us a look into what disabled people do when they become adults and taught us how to do so. Just like anyone else they make decisions with advice from a group of people they trust. It's humanizing.

# GRACE'S STORY

I was born in India where there was little awareness and support for people with Down syndrome. However, I was fortunate to have an incredible circle of support, including my family and even my neighbors. I was the first person with Down syndrome to attend the neighborhood preschool alongside my friends.



When I was 4 years old, we moved to the U.S. While there is more awareness here, many challenges remain the same. In elementary school, my parents had to constantly advocate for me to be placed in a co-taught class and ride the same bus as everyone else.



The system often focuses on limitations and exclusion, and even 34 years after the ADA, an inclusive society remains an aspiration. But in my home, we always focused on opportunities and possibilities, not on limitations.



I DECIDE has helped me build confidence in making decisions independently and knowing when to ask for help. It's important to highlight that everyone, needs support in decision-making at times. My disability does not define me.



Through I DECIDE, I've become more independent, launched two startups—Chai Ho Teas and the LetMe Do It app—and gained the confidence to believe in myself and understand that it's okay to make mistakes sometimes.

# ANGAD'S JOURNEY

## SDM IS A FLEXIBLE TOOL BUT...

“[T]here are myriad of differences on how self-determination manifests across cultural groups” (Goode, 2019)

Autonomy, individualism, and self-determination are moral principles deeply rooted in Western thinking and culture (Aichroth, et al., 2002; Clements, 2004).

“The culture of Western special education, focused as it is on the dominating discourse of Anglo-American beliefs, places value on certain settings, such as independent living and work environments ...” (Smith & Routel, 2010).

# THERE ARE OTHER WAYS OF BEING

- We need to **consider other ways of being** and **honor cultural differences** that value a more collective social model of human relations...and we can!
- “**Self-determination** is **individually** and **culturally relative**. . . . [T]ools such as **person-centered planning processes, circles of support, individualized funding, and support brokerage** are **essential elements in bringing choice, control, and power** into the lives of people with disabilities and their families” (Smith & Routel, 2010).

# Diversity, Equity, & Inclusion: Advancing SDM through Community Partnerships in Massachusetts

- **What?**

- Make Supported Decision-Making (SDM) and other alternatives to guardianship **more accessible** to underrepresented and underserved communities
- **Year-long project** funded by the **Massachusetts Developmental Disabilities Council** (2023-2024)



Center for Public  
Representation

# MDDC SDM 2023-24 Grant - How?

- Pilot and evaluate **culturally competent trainings to educate parents and other family members of people with IDD** about SDM and other options
  - **Intentionally embed project** within CPR's Racial Equity Initiative
  - Focus on **family members of transition-age youth and young adults with IDD**
  - Partner with **people with IDD, family members, and other community leaders**
  - Draft a **report** with lessons learned, outcomes, and recommendations for adaptation and replication



**Final Report**

# Community Partnerships



- Advisory Committee
- Conexiones Latinx-MA
- The Arc of Greater Haverhill-Newburyport
- Black Autism Coalition
- Parent/Professional Advocacy League (PPAL)
- Cambodian Mutual Assistance Association
- And more!





# Practical Strategies

- Ensuring **mutually beneficial relationships** with community partners
- **Including and compensating people with lived experience** as subject matter experts
- Developing training materials and presentations in **partnership with members of impacted communities** – focus groups, planning sessions
- Being **flexible in format** of educational sessions
- Recognizing **limits of simultaneous interpretation**
- **Screening interpreters**



# Personal Perspective on SDM and Culture



# Some Lessons Learned

- There is both an **appetite and need** for culturally accessible information about SDM in Massachusetts.
- While we have created new resources for families, there is **still a huge gap in accessible information** for many communities.
- The **most compelling and impactful stories** come from people with disabilities and their families.
- **We have more to learn and do.** This project is only the beginning
- For more information, see **CPR's SDM DEI webpage**



**CPR SDM  
DEI webpage**

- ▶ **Learn from community leaders** and follow their lead
  - ▶ They are **key to understanding** and educating yourself
  - ▶ **Be curious** -- what is valued in this culture, what it means
- ▶ **Involve people from the culture from the start**
- ▶ Recognize successful **relationship building takes time**
- ▶ **Critically consider your own processes**
- ▶ **Spend time with the community**, read material produced by the community, follow community leaders and organizations on social media (with caution)

# CULTURAL HUMILITY IN PRACTICE





**No White Saviors**  
@nowhitesaviors



6) Accept that you can't be an expert in what's best for a community you are guest in. You need to be a student & you need to practice far more humility than you've been conditioned to. Your degrees & accolades don't make you best fit to fix complex problems in other cultures.

# DECIDE Questions w/Cultural Considerations: CHAMPION

## General Considerations

The person supporting the process

- Must be chosen by the person\*
- Must be committed
- Must be able to engage and teach others
- Must be creative and willing to try another way
- Must know the person really well, understand their communication, can distinguish between true yes and no/interest and disinterest
- Familiarize yourself with the process, it won't happen all at once but look for and use every opportunity to offer choice and control.

## Cultural Considerations

- An authority figure
- A peer
- An Older person
- Another disabled person
- A person without disabilities
- A Language peer
- A person who shares your culture



# DIRECT

## General Considerations

- Where do you want more choice and control?
- What goals do you have?
- What about (work, home, relationships, health, money management, spirituality, community involvement)
- Do you want more friends? Do you want more choices about your free time?
- What do you want to learn?
- What's important to you in your life? What could be better? What don't you like about your life?
- Once a category or two is identified use
  - Sample brainstorming questions
  - Stoplight tool to get more specifics

## Cultural Considerations

- What does your community want for you?
- Of those goals what do you want for yourself?
- What typical teen/adult cultural experiences are important to you?
- What cultural experier are important to you?



# ENLIST

## General Considerations

- Who listens to you?
- Who is good at helping with (what ever the goal is)?
- Who helps you do the things you want to do?
- Who can you talk to about hard things?
- Who responds to you, answers or comes when you ask?
- Who wants you to have a good life?
- Make suggestions and double check

## Cultural Considerations

- Who do others in your community respect?
- Who understands you and your culture?
- Who is available to help you?
- Are there people who should not help you?





# CHOOSE

## General Considerations

- How do you learn best; do you want to hear, see, read, try, watch others?
- How do you want to be supported to make decisions; one on one, in a group with trusted people, send emails with questions, discuss in person?
- What choices and decisions are you already good at making? How did you learn that?

## Cultural Considerations

- How do you best communicate?
- How do folks in your culture learn and teach?
- How do decisions get made in your culture?
- What's most important for people of your age in your culture?



# INFORM

## General Considerations

- Who do you want to respect your decisions?
- Who needs to know about this process?
  - Doctors, teachers, banks, service providers
- Do you want to use a document
  - SDM Agreement
  - Release of Information
  - Power of Attorney
  - Advance Directive
  - Psychiatric Advance Directive

## Cultural Considerations

- Who in your community is it important to tell?
- How should you inform your community? Document, video, letter, meeting, some other way?



# DETERMINE

## General Considerations

- How will we know we are meeting your goals?
- How will we know you are learning these skills?
- How will we know this is working the way you want it to work?

## Cultural Considerations

- Where do you want to be in your culture?
- What does leadership look like in your culture?
- What does successful adulthood look like in your culture?



# EXPERIENCE

## General Considerations

- What opportunities do you need/want to practice?
- When can/should that happen? How often?
- What does practicing look like? (Can't learn to swim on a soccer field)
- What happens when you make a mistake?
- What happens when what you want is different from what others want?
- How do we make sure you stay safe will learning (safe failing, guardrails)?

## Cultural Considerations

- Are there things that are not allowed or unacceptable in your culture?
- How do folks in your culture take on new roles as leaders or adults?



# Tips



- Follow the person's lead
- Stay curious
- Use what you know, but don't cut off new ideas
- What else do you know, can you tell me/think of one more thing
- Be prepared to try and fail and try again
- Respectful guessing
- It's a feedback loop, you are both learning the whole way



# LetMeDolt



**Apple**



**Android**

- SDM is flexible
- Based on user needs and preferences
- Customizable based on how you live your life
- LetMeDolt (a SDM platform) is not a template for life decisions, it encourages independent decision making



QUESTIONS



- ▶ Aichroth, S., et al. (2002). Creating a new system of supports: The Vermont self-determination project. *Rural Special Education Quarterly*, 21 (2), 16-28.
- ▶ Clements, E. (2004). The limits of self-determination. *Convergence*, 37(2), 65-77.
- ▶ Goode, T. (2019), Self-Determination: Cultural Differences in Perception and Practice, IMPACT 32, <https://publications.ici.umn.edu/impact/32-1/self-determination-cultural-differences-in-perception-and-practice>.
- ▶ Smith, P., & Routel, C. (2009). Transition Failure: The Cultural Bias of Self-Determination and the Journey to Adulthood for People with Disabilities. *Disability Studies Quarterly*, 30(1). <https://dsq-sds.org/index.php/dsq/article/view/1012/1224>.

## CITATIONS



# RESOURCES

- ▶ I DECIDE Georgia,  
<https://idecidega.org>
- ▶ The Georgia Advocacy Office,  
<https://thegao.org>
- ▶ Center for Public Representation's  
SDM Training and Technical  
Assistance Center,  
<https://supporteddecisions.org>
- ▶ Center for Public Representation,  
<https://www.centerforpublicrep.org>
- ▶ Center on Youth Voice, Youth  
Choice, <https://youth-voice.org>

# Feedback & Data Collection Survey Supported Decision-Making Project



As part of our grant from the Georgia Council on Developmental Disabilities, we are asked to collect demographic data and survey responses from participants.

Please answer these 10 questions. We would love your feedback at the end so we can make improvements and adjustments



**THANK YOU!**

# CONTACT US



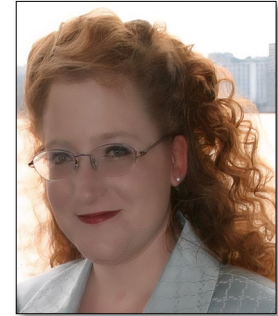
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