



Advancing Rights and People-Centered Approaches: Equity Policy for New Mexicans with Disabilities

Background History

Dominant Paradigm: The Medical Model

Disability has been used as a justification for exclusion from full and equal rights and privileges of U.S. society since the mid-19th century. The oppression of marginalized groups and their exclusion from full membership in society was justified through labeling them with disabilities [1]. The Eugenics movement that believed in the superiority of the able-bodied Caucasian males and enacted policies against those who did not fit into this group, along fears about the genetic makeup of society, only increased fear of and discrimination against people with disabilities [1].

Those with disabilities have historically been labeled as deficient. The medical model operationalized the deficit model by creating a standard of health that was based on a medical archetype of “normal” whereby anyone who deviated was deficient. The model places the responsibility on the person with a disability to fit into the established norms within society [2]. Numerous policies including the institutionalization of people with disabilities, the sterilization of people with disabilities, exclusion from schools, medical experimentation and various forms of segregation from society have used the medical model as a justification [3].

The deficit paradigm has transcended medical services and permeated nearly every system of services. Andrew Imparato, CEO of the American Association of Persons with Disabilities (AAPD) put it,

Social Security, Supplemental Security Income, Medicaid and Medicare. Those four programs are based on a definition of eligibility that goes back to 1956. . . . [W]e are in 2008 requiring 18-year-olds with significant disabilities to go down to the federal government and swear that they’re unable to work in order to get support [4].

The issue with this approach is best summed out by Blanck [4] who explains, “As long as disability is viewed as a problem to cure or as an incapacity to participate in the labor force, and not tied to rights and justice issues, the potential for individuals with disabilities to accumulate assets and the right to live in the world will be stymied” (p. 400).

Alternative Models: The Social Model

The emphasis within this model is how society needs to change and adapt to the person with a disability, rather than the other way around [2]. Within the social model of disability, the societal barriers

to full participation within society are defined as needing to change rather than the person with a disability. Notably, the social model is also a strength-based model that has an explicit goal of inclusion within society. Various civil rights laws that have emerged for People with Disabilities serve as examples:

- Section 504 of the 1973 Rehabilitation Act, for instance, states that any organization that receives money from the federal government must be accessible for people with disabilities.
- The Individuals with Disabilities Education Act also places the onus on the schools to ensure that students with disabilities receive a free and appropriate public education in the least restrictive environment.
- The Americans with Disabilities Act goes even further by explicitly naming and prohibiting various types of societal discrimination against people with disabilities [4].

Notably, the courts have also adopted the use of the social model's emphasis on rights and inclusion. In addition to cases related to the three aforementioned disability laws, the 1999 *Olmstead v. L.C.* decision affirmed the right of individuals to live in and receive services in the community rather than in institutions.

Alternative Models: The Minority Group Model

Within this model, the focus is on historical challenges faced by people with disabilities as a whole and efforts to rectify those challenges [2]. In doing so, those who subscribe to the minority group model argue that this decision laid the foundation for the inclusion of students with disabilities in public schools [2]. Within this model, activism by individuals with disabilities such as Ed Roberts leads directly to benefits for people with disabilities, which in this case would be the creation of independent living centers [2].

Despite these laws and the disability civil rights movement, equality for people with disabilities is lacking. For example, when examining the economic equality and empowerment of people with disabilities, Blanck [4] concludes that "people with disabilities continue to be excluded from these opportunities" (p. 399). In employment, people with disabilities also face lower pay, less benefits and less job security [4].

An Alternative Approach: Person-Centered Approach

Person centeredness focuses on what is important to and for a person. Attributes of person centeredness include: empowerment, self-determination, meaningful lives, inclusion, quality of life, dignity of risk, autonomy, values social roles, and contribution. Person centered thinking values and supports individuals with intellectual and developmental disabilities to make informed choices and exercise the same basic, civil and human rights as other citizens, including dignity of risk. Person centered planning is a way to help a person plan their services and supports, is an ongoing process that identifies what is important to and what is important for a person, and ensures the individual is at the center of the process and is encouraged to direct the process as much as possible. This involves listening, empowering, encouraging, and supporting. Person centered practice is aligning service resources that give people access to the full benefits of community living and ensure they receive services in a way that helps them achieve their individual goals. Key elements of person centered systems include people with IDD having rights like everyone else, supporting people to live life like everyone else, supporting people

to lead their lives, empowering choice making, supporting dignity of risk, supporting community inclusion, connection and engagement, using a person centered planning process and developing individualized person centered plans.

In an effort to redress the aforementioned focus on the medical model within Medicare and Medicaid home and community-based services, the Centers for Medicare and Medicaid Services released the Home and Community Based Services Settings Final Rule in 2014 [5, 6]. The rule shifts the focus from agency-centered service models to a more person-centered model focused on the integration of people with disabilities into their communities.

The Problem

The problem in New Mexico is that although the state of New Mexico has state policies and service standards as well as federal mandates that require the practice of being person centered, the degree of operationalizing those rules varies widely across the Home and Community Based Services system. Some provider agencies offer great freedom and creativity for people to make choices and live the life they choose, while others remain very provider-centric, focusing on the best interests of the agency not the person being served. Furthermore, in many rural areas, there is a very limited number of providers to choose from. This issue is significant because New Mexico is a largely rural state.

In addition to well-known disability rights laws such as the Americans with Disabilities Act, the Centers of Medicare and Medicaid Services (CMS) in 2014 published a Final Rule making changes to Home and Community Based Services (HCBS) waivers. “The intent of the Final Rules is to ensure that individuals receiving long-term services and supports through home and community based service (HCBS) programs under the 1915(c), 1915(i) and 1915(k) Medicaid authorities have full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate and to enhance the quality of HCBS and provide protections to participants.” [5, 6]. More specifically the Final Rule requires that HCBS settings are integrated in and support access to the greater community, provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources, ensure the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services, ensure an individual’s rights of privacy, dignity, respect, and freedom from coercion and restraint, optimize individual initiative, autonomy, and independence in making life choices, and facilitate individual choice regarding services and supports, and who provides them. Additionally, the Final Rule requires specific rights of individuals regarding their living situation, privacy within their own home, etc. All of this must be supported by specific assessed need, justified in the person-centered service plan, and documented in the person-centered service plan, (CMS 2014) A true person-centered system supports, promotes and encourages individuals living with disabilities to live the life they choose.

Surveys were conducted by the New Mexico Department of Health, Developmental Disabilities Supports Division in 2017 to establish whether HCBS service providers were compliant with requirements issued by the CMS Final Rule, to include person centered practices. Surveys for waiver recipients also took place. In general, the results of the surveys showed a high degree of compliance with Final Rule Requirements. Close examination of the answers of individuals receiving waiver services showed there is needed improvement in person-centeredness in the areas of having choices of housing and having nonmedical transportation more readily available for their use,

Written feedback from the waiver participants surveys ranged from being satisfied to the other end of the spectrum, not being satisfied. Some examples include:

“I talk to the staff. We do a lot of activities as a group and the girls in the group don’t always like to do what I want to do so we decide as a group to do whatever it is, we want to do for the day. I don’t mind.”

“I have to ask permission. That is why I want to have a place of my own. I don’t want to ask permission to do things.”

“I can have visitors in the home whenever I want. I spend a lot of time with my girlfriend in my home.”

“Honestly no, I don’t like it. Most of the consumers are younger than me mentally. Or the consumers are a lot older than me. I don’t relate to a lot of people here. I have an attachment disorder where I get attached to people easily. The staff move or leave this agency often and I get crushed when they leave.”

New Mexico’s grassroots Know Your Rights Campaign, designed to educate, promote and implement the CMS Final Rule, gathered data from multiple sources over several years to determine if people utilizing Developmental Disabilities Waiver services in New Mexico actually have choices of where they live, how they spend their day, who they live with, etc. Thirty town hall meetings were held in the State of New Mexico between 2016 and 2020. They were attended by 1,443 people including self-advocates, family members, providers and state employees. A prominent theme from self-advocates was that they often were not listened to and decisions were made for them without talking with them or respecting their wishes. This applied to some provider agency staff as well as some guardians.

A prime example demonstrating the disconnect is seen in this quote from a person receiving waiver services: “Will they be able have party’s sent they took away party’s in the group homes and have real candles can they have snakes (snacks) if they want to if they don’t need on a diet, can they eat what they want just because someone else needs to does not mean they should have as well can they get rifles to jobs that are not on 9-5 work days and get back home can they have an animal that is not for service they can have a ride for help with him or her can we live where there is no dugs and on a good runing bus rut and not have to be buged for money?”

The critical importance of being as independent as possible was also a recurring theme. An advocate who receives services through the DD Waiver states, “I love having choices because it makes me feel independent”. Another strong advocate on the DD Waiver describes the importance of having choices this way “It means I have my own independence. I can do things on my own. I have the support of others if I need it, but I can mostly do it on my own”. An individual in Silver City stated, “I want to be able to have my friend over and drink coffee”. Statements like these point to the importance of choice, in big ways and little ways, in everyone’s lives.

The role and power of a guardian in a person’s life was often brought up by waiver participants as well as guardians during the Town Halls. Some people described guardians who listen to and respect their choices while others described guardians who are very restrictive and do not take the time to listen to what the person thinks or choices they would like to make.

New Mexico’s IDD system has improvements to make in order to become a *true* person-centered system. The following policy options will move New Mexico’s system towards our vision of a state where people with intellectual and developmental disabilities are part of the fabric of their communities and live the lives of their choice.

Figure 1 highlights selected memorable actions taken in New Mexico and by the federal government between 1970 and 2020. These actions were ostensibly taken to improve to the lives of people who live with disabilities. Figure 1 can be found immediately following the References page of this paper.

Policy Options

There is an immediate need for the State of New Mexico and providers of Home and Community Based Services to adopt and/or adhere to person-centered planning, thinking, practice and policies. As mentioned previously, the Centers for Medicare and Medicaid Services (CMS) has issued a Final Rule that requires states and providers working with HCBS waivers to be compliant by March 17, 2022. While NMDOH reflects person-centered planning in its waiver service standards, it is reported by many individuals receiving services that there are varying levels of compliance to these standards by providers. Research shows that, if adopted, the following three options increase the likelihood that individuals participating in these services will live the life they choose, which is the goal of person-centeredness.

Option 1: Supported Decision-Making should be both taught and implemented by state agencies, providers, and disability rights advocacy groups in New Mexico.

States have often removed rights from people with disabilities in the name of protecting them, using Guardianship as the main mechanism to do so [7]. There is also the potential for widespread abuse within the Guardianship system [7, 8]. Furthermore, research has not demonstrated the benefits of Guardianship for the person with a disability and in fact reveals decisions made based on incomplete information [9].

While self-determination has been established as best practice for people with disabilities, Guardianship removes the rights from people with disabilities and transfers them to an alternate decision maker [9]. Also, full Guardianships, which are the more restrictive type of Guardianship, is the one most commonly recommended [9]. This is in spite of the fact that there are limited forms of Guardianships where individuals retain more of their legal rights than under a full Guardianship. Jameson et al [9] found that school personnel are not involved in the training and education on Guardianship, despite the fact that 18 is the median and mode age for Guardianship appointments. This reliance on Guardianship at a young age seemingly disregards research has equated self-determination with better life outcomes [9]. Appendix A details the current types of Guardianships and alternatives to Guardianship available in New Mexico.

An alternative that is gaining acceptance at both the state level in the United States and internationally is Supported Decision-Making. Supported decision making is a system where the individual remains the legal primary decision maker to the maximum extent possible while receiving assistance from support persons [10]. This idea differs from Guardianship where another person or entity is given the legal right to make decisions on behalf of a person. Supported decision-making has also arisen out of the American disability rights movement independent of international law [8]. Article 12 of the UN CRPD includes safeguards to

respect the rights, will and preferences of the person...free of conflict of interest and undue influence...proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body" [10].

Supported decision-making is recognized in practice to have links to self-advocacy, mechanisms to protect a person's best interest, use of informal support networks when possible, a selection by the individual of support persons, resolving conflicts with the individual's will and preferences and safeguards to ensure the primacy of the person with a disability [7]. Supported decision-making models provide the individual with the legal decision-making authority with support consisting of free-will associations that do not supplant the legal authority of the person with a disability [9]. This in turn places people with disabilities on an equal legal level as other citizens while promoting the inclusion of that person in society and their growth as a citizen of that society [8].

Notably, funding for the Guardianship Program at the New Mexico Developmental Disabilities Planning Council for individuals at 150% of the poverty line or below is limited. Resources are currently at capacity and limited funding has led to a wait list for services. Supported decision-making could help alleviate the burden on agencies and programs such as these.

Notably, supported decision-making is consistent with best practices engrained in international law and laws in the United States. Jameson et al [9] notes that "law and policy already encouraged self-determination and community integration (e.g., ADA, 1990; Developmental Disabilities and Bill of Rights Act, 2000; Olmstead v. L.C., 1999; Rehabilitation Act of 1973)" (p. 40). Texas, for instance, implemented a guardianship reforms bill that increases the due process rights of those in guardianship proceedings while increasing the burden of proof on those seeking a guardianship [8]. A Ward's Bill of Rights was also passed that affirms to the maximum extent possible the rights of alleged incapacitated persons [8].

Finally, supported decision-making incorporates many best practices of person-centered planning. Supported decision-making provides people with disabilities the opportunity to make choices and take responsibility for the outcome of those choices [8]. This concept is often phrased as "Nothing About Us Without Us" in the disability rights movement. Embedded in the responsibility for their choices is the concept of dignity of risk. This concept states that people with disabilities should be allowed to make their own choices regardless of what could happen and that there is learning that takes place from choices with less than ideal outcomes. Doing this takes the focus off of what is wrong with the person and shifts the focus to whether or not society adequately supports the needs and desires of the person (Carney, 2017) [11]. In other words, "Supported decision-making locates support in trusting, personal relationships" [8]. Notably, in states such as Texas, this allows supportive decision-making to serve as an alternative to an already overburdened and under resourced Guardianship system [8]. It can do this while building on best practices in law and person-centered care to actualize the full potential of individuals with disabilities.

New Mexico has the opportunity to introduce Supported Decision-Making into the state through passing a bill on Supported Decision-Making. As noted in Table 2, there are important considerations to take into account in a Supported Decision-Making bill. Table 3 notes that various ways in which states across the United States have implemented Supported Decision-Making. New Mexico has notably taken steps to introduce supported decision making in New Mexico. HM 23 was written during the 2020 Legislative Session for the expressed purpose of studying and reporting on supported decision-making as an alternative to Guardianship and Conservatorship. In that same session, HB 67 was also proposed for the same purpose, with an allocation of \$50,000 for the costs of starting and operating a task force. . HB 94 on a Supported Decision-Making taskforce was proposed in 2021. None of the bills passed, but it demonstrates that there is interest in Supported Decision-Making in New Mexico.

Category of Finding	Summary of key findings
Pros	<p>The person who needs assistance retains legal capacity to make decisions within the Supported-Decision Making Model.</p> <p>Supported Decision-Making uses already existing personal relationships to provide assistance to the individual needing assistance.</p> <p>Supported Decision-Making uses a strength-based model when identifying the needs of the person needing assistance.</p> <p>Supported Decision-Making as a mechanism can serve as an alternative to Guardianship, which can avoid further taxing the Guardianship system.</p> <p>Self-determination is a foundational principle of Supported Decision-Making.</p>
Cons	<p>With dignity of risk, there is always the potential that a person can make choices that are harmful to themselves.</p> <p>There is the potential for family members or natural supports to misuse their guidance and interact with the person needing assistance in a paternalistic way.</p> <p>There can be the risk of inadvertent harm or even abuse if family and friends are not aware of or invested in the foundational principles of the Supported Decision-Making model.</p> <p>This model of decision-making could be more difficult for those without close family or friends.</p> <p>The proper laws and legal infrastructure need to be setup to enable the full potential of Supported Decision-Making.</p> <p>Need further research on the outcomes of Supported Decision-Making.</p>

Resource use, costs and / cost-effectiveness	Money might be necessary to establish the legal framework and training of individuals in the Supported Decision-Making model. Long-term, however, the use of resources will be far more efficient than the extensive resources required for Guardianships.
Stakeholders' view and experience	Individuals who utilize supported decision-making are able to retain capacity and are supported to make their own decisions.
Additional considerations for policy making	Different states enact Supported Decision-Making in different ways, so a decision will have to be made with regard to how Supported Decision-Making is enacted.

Option 2: The use of Personal Outcome Measures® should be implemented throughout the HCBS system in New Mexico.

When person-centered planning is used, it is important to also implement a way to measure whether desired outcomes are being achieved.

The Personal Outcome Measures® (POMs) were developed by The Council on Quality and Leadership (CQL). They are a quality of life measurement tool that can be used to create more person-centered supports and services [12]. In a Personal Outcomes Measure® interview, 21 indicators are used to understand the presence, importance and achievement of outcomes involving choice, health, safety, social capital, relationships, rights, goals, dreams, employment and more. The insight gained during a Personal Outcome Measures® interview can be used to inform a person-centered plan, and at an aggregate level, can be used to influence an organization’s strategic plan. These measures are an effective data set for valid and reliable measurement of individual quality of life [13]. The measures can help determine if supports for persons with disabilities are meaningful, and if they help foster important relationships and access to their overall safety and stability [12].

Quality of life (QOL) measurements are important for individuals with disabilities as they measure beyond just clinical health components to look at all components that go into life-satisfaction. However, while different quality of life measurements are commonly used, not all measurement tools are person-centered. The POMs have been adapted, tested, and validated. All practitioners must be certified to administer the interview to maintain the validity of the measures. Tennessee, Indiana, Colorado, and New York have all incorporated Personal Outcome Measures® and provide training and certification from the state in efforts to improve person-centered care.

Using CQL’s POMs can help ensure agencies who provide services to any of New Mexico’s HCBS 1915(c) waivers will be in line with the CMS Final Rule by providing more person-centered measures of QOL. For example, the Personal Outcome Measures® distinguish between access to a community and

integration within a community. This would help identify if CMS’s ruling that HCBS waivers must provide meaningful community opportunities is being followed [12].

In Fall of 2019, NMDOH DDSD consulted with CQL to determine the feasibility of pursuing a network certification, which includes training on the use of Personal Outcome Measures® and many other services. New Mexico’s current budget restraints does not allow NMDOH DDSD to pursue a full network certification. They are interested in returning to this goal when budget constraints are loosened. It appears possible, however, to pursue only training on the use of Personal Outcome Measures® at a fraction of the cost of network certification.

Category of Finding	Summary of key findings
Pros	<p>Can help New Mexico meet milestones for CMS Final Rule Transition Plan.</p> <p>Can help tear down old mindsets providers and others may have about I/DD.</p> <p>Can help all who work with people who have I/DD to truly begin to help the individual with I/DD to live their best life.</p> <p>Can contribute to New Mexico to become – and to be seen as – a leader and model in using the person-centered approach.</p> <p>Can help to forge a deeper understanding and trust between individuals with I/DD and NMDOH DDSD.</p>
Cons	None identified
Resource use, costs and / cost-effectiveness	Adopting POMs will require an initial capital outlay to train employees in how to apply this measurement tool. The training will be continuous as employees enter and exit the system.
Stakeholders’ view and experience	Stakeholder’s view is expected to be varied. A representative from Tennessee who adopted the use of POMs stated that it is imperative to be transparent in the process and to maintain strong and positive communication with providers.

Additional considerations for policy making	Many states have adopted the use of POMs including Tennessee, Indiana, Colorado, and New York with positive outcomes.
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Option 3: The use of Peer Mentoring should be included as a service in HCBS 1915(c) waivers in New Mexico that provide service to intellectual and developmentally disabled (I/DD) individuals.

Person-Centered Planning is widely used as an approach to individual program planning for individuals with intellectual and/or developmental disabilities. It aims to develop collaborative supports for the individual that focus on respect, positive relationships and community participation. Additionally, it focuses on the individual receiving services being able to make their own decisions and be able to live life the way that they want [14]. When the Centers for Medicare and Medicaid (CMS) presented the Final Rule in 2014, part of its aim was that all Home and Community Based (HCBS) waivers use the person-centered approach for individual program planning.

Peer mentoring is another way to support an individual to live life the way they choose, and it fully supports person-centered planning. Peer Mentors are individuals with intellectual or developmental disabilities (I/DD), who have a unique skill level from their lived experiences, passing along encouragement and support to help others construct their own advocacy. A Peer Mentor offers firsthand experiences on how to use resources available to people with I/DD. Peer Mentors can help guide individuals towards greater self-advocacy, empowerment and personal responsibility for their own success.

Peer mentoring has long been used in education, particularly for students transitioning from high school to college, in businesses with new employees, and in the mental health field, particularly in the two distinct areas of depression and sobriety with positive results. People who benefit from Peer mentoring in these areas are individuals diagnosed with intellectual and/or developmental disabilities [15, 16].

Peer mentors are paired with individuals who believe they can benefit from something the peer mentor has experienced (including trauma) or something the individual desires to experience, such as achieving certain goals (in health, education, employment, building relationships, etc.).

Numerous states include peer mentoring as a HCBS 1915(c) waiver service including Virginia, Maryland, Washington and New York. New York defines their peer mentoring waiver service this way:

Peer Mentoring is an individually designed service intended to improve the waiver participant's self-sufficiency, self-reliance, and ability to access needed services, goods, and opportunities in the community. This is to be accomplished through education, teaching, instruction, information sharing, and self-advocacy training.

Peer mentoring can be used in many ways. Here are two examples from the Washington State Developmental Disabilities Council:

Josh is planning on going to an upcoming school formal dance. Josh hires Bob, an 18-year-old high school senior who has a peer mentoring contract and has been to many high school dances

since he started school. Bob and Josh connect and talk about what type of clothes people usually wear to dances. Bob tells Josh where a local tux store is and then goes to the dance with Josh and shows him where the refreshment table is, how to ask someone to dance, etc.

Sally is new to the area and wants to learn the bus routes. She hires a peer mentor, Donna, to show her the ins and outs of the local transit system, including how to stay safe and ask for help if she needs it.

In New Mexico, the Mi Via Self-Directed HCBS 1915(c) Waiver has an advisory committee that is a subcommittee of the Advisory Council on Quality (ACQ). It is called the Mi Via Advisory Committee (MVAC), and it supports the Mi Via Self-Directed Waiver program. The MVAC is composed of many self-advocates, family members and self-directed waiver recipients. This committee has repeatedly recommended that advocates, people with IDD, be the leaders, trainers and educators for the self-directed community. Peer mentoring is something the MVAC has advocated for since the development of the Mi Via Waiver.

Category of Finding	Summary of key findings
Pros	<p>Benefits of mentoring program participation for youth with disabilities include improved employment and career-related decisions, transitions to adulthood (as well as college and work), postsecondary education goals, and independent living skills.</p> <p>Peer mentoring focusing on health education is shown to increase physical activity, hydration knowledge, social supports and positive health behaviors</p> <p>Peer mentoring focusing on emergency preparedness significantly increased knowledge in this area.</p>
Cons	<p>Potential harm may arise if peer mentors are not carefully trained and screened.</p>
Resource use, costs and / cost-effectiveness	<p>Peer Mentoring can be added to a HSBC 1915(c) waiver as a service. The cost to the state will be largely offset by federal government reimbursement.</p>
Stakeholders' view and experience	<p>There is expected to be little opposition to peer mentoring. The I/DD community, shown through feedback given in the Town Hall meetings conducted from 2016-2020, are supportive of this service.</p>

	The Mi Via Waiver Advisory Council has requested that Peer Mentoring be added to the services Mi Via offers.
Additional considerations for policy making	Including and embracing community programs and organizations that work with and enhance the lives of people living with I/DD, will make adding peer mentoring as a program to support individuals living with I/DD more robust.

Additional Policy Considerations

At the heart of this policy brief is the concept that person-centeredness is key to facilitating people with I/DD to live the lives of their choosing. Three policy options were presented that will support New Mexico in strengthening their person-centered approach. Each of the policy options have strong supporters in this state.

In New Mexico’s current financial climate, the most challenging option to implement will likely be the use of Personal Outcome Measures® because of the cost involved. While it is not currently feasible, it will be a critical tool to add to person-centered planning since it measures all components that go into life satisfaction. Without POMS, it will be difficult to know whether the person-centered planning for each person is successful. It is recommended that this policy option is revisited when New Mexico is not in a budget crisis.

Applying the concept of Supported Decision-Making, particularly in the area of Guardianship, is essential to embracing the person-centered approach. It is also completely feasible to enact in New Mexico. It will empower and enable people diagnosed with I/DD to make their own choices and live a life of their choosing, and it will cost little. Not enacting Supported Decision Making will mean that many people with disabilities will not have the opportunity to make their own choices and to take responsibility for the outcome of those choices.

Making Peer Mentoring a waiver service will make it available to all people using HSBC 1915(c) waiver services for individuals with I/DD in New Mexico. The key to carrying out this idea is to verify that people using the Supports Waiver and the DD Waiver are also interested in having this service available. (People on the Mi Via Waiver have already made it clear that they would like this service added.) HSBC 1915(c) waivers would then have to be amended then submitted to CMS and approved. Adding Peer Mentoring to waiver services will strengthen support for people with disabilities including support for reaching education, health and employment goals.

References

1. Baynton, D.C. *Disability and the Justification of Inequality in American History*. Fifth Edition. New York: Routledge; 2017:17-34.
2. Darren, M., & Timothy, L. Disability history: Humanity worth defending. *The Ohio Social Studies Review*. 2013; 50(2), 15-21.
3. Sabatello, M. (2013). Human Rights and Disability Advocacy. In: *A Short History of the International Disability Rights Movement*. Pennsylvania Studies in Human Rights. University of Pennsylvania Press; 2013:13-24.
4. Blanck, P. "The Right to Live in the World": Disability Yesterday, Today and Tomorrow. *Texas Journal on Civil Liberties & Civil Rights*, 2008; 13(2), 367-401.
5. Centers for Medicare and Medicaid Services. Home & Community Based Services Final Regulation.
<https://www.medicaid.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html>
6. Centers for Medicare and Medicaid Services. Fact Sheet: Home and Community Based Services. 2014. Available at:
<https://www.cms.gov/newsroom/fact-sheets/home-and-community-based-services>.
7. Dinerstein, R. Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Support Decision-Making. *Human Rights Brief*, 2012; 19(2), 8-12.
8. Theodorou, E.J. Supported Decision-Making in the Lone-Star State. *New York University Law Review*. 2018; 93(4), 973-1013.
9. Jameson, J.M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., and Hoyle, D. Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities. *Research and Practice for Persons with Severe Disabilities*. 2015. 40(1), 36-51.
10. Gooding, P. Supported Decision Making: A Rights-based Disability Concept and its Implications for Mental Health Law. *Psychiatry, Psychology and Law*. 2013; 20(3), 431-451.
11. Carney, T. Supported Decision-Making in Australia: Meeting the Challenge of Moving from Capacity to Capacity-Building? *Law in Context*. 2017; 35(2), 44-63.
12. Friedman, C., & VanPuymbrouck, L. The impact of people with disabilities choosing their services on quality of life outcomes. *Disability and health journal*. 2019; 12(2), 187–194.
13. Friedman, C. The personal outcome measures[®]. *Disability and Health Journal*. 2018; 11(3), 351–358.
14. Claes, C., Van Hove, G., Vandeveld, S., van Loon, J., and Schalock, R. Person-Centered Planning: Analysis of Research and Effectiveness. *Intellectual and Developmental Disabilities*. 2010; 48(6), 432-453.
15. Schwartz, A.E., Kramer, J., Rogers, E. S., McDonald, K.E., and Cohn E.S. Stakeholder-driven approach to developing a peer-Mentoring intervention for young adults with intellectual/developmental disabilities and co-occurring mental health conditions. *Journal of Applied Research in Intellectual Disabilities*. 2020; 33(5).

16. Jones, M., Budke, K., Brown, O., Caldwell, R., Claybern, C., Jacobs, R., Robinson, M. Building Inclusive Communities Through Peer Mentoring: A Tool for Change. *Journal of Inclusive Postsecondary Education*, 2020; 2(2).

Appendix A

Levels of Guardianship and Alternatives to Guardianship courtesy of the New Mexico Developmental Disabilities Planning Council's Office of Guardianship (n.d.)

Type of Guardianship or Alternative to Guardianship	Definition
Guardianship	<p>Guardianship is a legal process that may remove considerable rights from an individual. It should only be considered as a last resort and when there are no least restrictive forms of intervention, such as a Power of Attorney or a decision maker designated under an Advance Directive.</p> <p>Guardianship is the most restrictive form of intervention and should be sought only in cases where an individual has limited decision making capacity and needs support to make decisions on their behalf.</p>
Full or Plenary Guardianship	<p>A guardian is appointed by the court to exercise all legal rights and powers of the protected person after the court has found that the person lacks the capacity to carry out all the tasks necessary to care for their self or property.</p>
Limited Guardianship	<p>A guardian is appointed by the court to exercise limited authority and decision-making for the protected person if it is determined that the person is able to manage some but not all aspects of their personal care. A person for whom a limited guardian has been appointed retains all legal rights except those that have been specifically granted to the limited guardian by the court.</p>
Temporary Guardianship	<p>A petition for guardianship that has been filed alleging that immediate and irreparable harm will result to the alleged incapacitated person. The temporary guardianship shall last not more than sixty days.</p>

<p>Mental Health Treatment Guardianship</p>	<p>A form of guardianship tailored to grant the guardian authority to make substituted decisions regarding mental health treatment (including psychotropic medications) for individuals determined by the court to lack the capacity to provide informed consent, for a specified period of time not to exceed one year.</p>
<p>Power of Attorney</p>	<p>An alternative while the person is still capable and they understand what they are signing.</p> <p>“Durable” means it is still good once person is incapacitated.</p> <p>“Springing” means it is only good once person is incapacitated.</p> <p>the POA can be broad or specific.</p> <p>the POA must be notarized, and it is best if prepared by an attorney working for the person.</p>
<p>Representative Payee</p>	<p>Social Security's Representative Payment Program provides financial management for the Social Security and SSI payments of beneficiaries who are incapable of managing their Social Security or SSI payments. Generally, they look for family or friends to serve in this capacity. When friends and family are not able to serve as payee, Social Security looks for qualified organizations to be a representative payee.</p>
<p>Informal Arrangement with Family Members</p>	<p>A decision-making arrangement that is not defined or codified within a particular law.</p>
<p>Surrogate Decision-Maker Related to Healthcare.</p>	<p>One might designate any individual to act as surrogate by personally informing the health care provider.</p> <p>the following in descending order of priority:</p> <p>spouse, unless pending petition for divorce, etc.</p>

	<p>an individual in a long-term relationship of indefinite duration similar to the commitment of a spouse, and the individual and the patient consider themselves to be responsible for each other's well-being;</p> <p>adult child, parent, adult brother/sister, grandparent;</p> <p>an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values.</p>
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Appendix B

What Supported Decision Making Policy Looks like in Each State Courtesy of The National Resource Center for Supported Decision-Making (n.d.)

State	Description of Law Related to Supported Decision-Making
Alaska	Codifies Supported Decision-Making Agreements for adults and creates a statutory SDM Agreement form
Colorado	Requires the court to appoint a court visitor to interview the respondent and others and report to the court on the supported decision-making surrounding the respondent if the court appoints as an emergency guardian or special conservator a professional person or public administrator.
Delaware	<p>Created the option for Supported Decision-Making Agreements, with form to be issued by state agency</p> <p>Incorporated Supported Decision-Making services in the medical context of organ transplantation</p> <p>Requests the Public Guardian to, among other things, work with advocacy and state agencies to promote systemic reform and recommend changes in the law, procedure and policy necessary to enhance the provision of services for substituted and supported decision-making.</p>
District of Columbia	<p>Recognized that “student[s] who have reached 18 years of age may receive support from another competent and willing adult to aid them in their decision-making”</p> <p>Created the option for Supported Decision-Making Agreements, with form codified.</p>
Indiana	<p>Codifies Supported Decision-Making and recognizes Supported Decision-Making Agreements</p> <p>Urges the legislative counsel to assign to the appropriate study committee the topic of Supported Decision-Making as an alternative option to adult guardianship in probate courts.</p>

Kansas	Incorporated Supported Decision-Making services in the medical context of organ transplantation.
Louisiana	<p>Provides for Supported Decision-Making Agreements and requires petitioners seeking interdiction to, among other things, describe with particularity why less restrictive means are insufficient to meet the needs of the person.</p> <p>Prohibits discrimination against people based on disability in the medical context of organ transplantation and identifies Supported Decision-Making services as auxiliary aids and services.</p>
Maine	<p>An Act to Correct Errors and Inconsistencies Related to the Maine Uniform Probate Code and To Make Other Substantive Changes (incorporates Supported Decision-Making into the guardianship statute as a less restrictive alternative)</p> <p>Completely repealed and replaced Maine’s Probate Code and recognized and required consideration of less restrictive alternatives to guardianship, including Supported Decision-Making.</p> <p>Required Probate and Trust Law Advisory Commission to examine the concept of Supported Decision-Making, consult with interested parties, and make recommendations concerning inclusion of SDM in the Probate Code, including any proposed legislation, in a report no later than 1/15/17</p>
Maryland	Incorporated Supported Decision-Making services in the medical context of organ transplantation.
Minnesota	Recognizes Supported Decision-Making as a less-restrictive option that courts must specifically find will not work before appointing a guardian.
Missouri	Before appointing a guardian or conservator, the court is required to consider less restrictive alternatives, including Supported Decision-Making Agreements.
Nevada	Codifies Supported Decision-Making and recognizes Supported Decision-Making Agreements.
North Dakota	Codifies Supported Decision-Making and recognizes Supported Decision-Making Agreements

Rhode Island	Establishes the use of Supported Decision-Making as an alternative to guardianship and codifies an SDM Agreement form.
Texas	<p>Established a pilot program for improving service delivery models related to Medicaid that was designed to, among other things, promote alternatives to guardianship, including a Supported Decision-Making Agreement.</p> <p>Incorporates Supported Decision-Making and Supported Decision-Making Agreements into special education transition planning requirements.</p> <p>Amends the Supported Decision-Making Agreement Act to define the fiduciary duties the supporter owes to the adult with a disability and to provide for the designation of an alternate supporter to prevent a conflict of interest in the case of paid supporters</p> <p>Codified a bill of rights for people subject to guardianship, including the right to petition a court for relief to transition to a Supported Decision-Making Agreement.</p> <p>Codified comprehensive guardianship reform, including Supported Decision-Making and a Supported Decision-Making Agreement statutory form.</p> <p>Codified Supported Decision-Making and a Supported Decision-Making Agreement Statutory form</p> <p>Status: Enacted 6/9/15</p> <p>Established a volunteer-supported decision-making advocate pilot program for persons with intellectual and developmental disabilities and persons with other cognitive disabilities.</p>
Virginia	<p>Introduced version would have included an “Supported Decision-Making Act,” including, among other things, Supported Decision-Making Agreement provisions for adults with intellectual or developmental disabilities. The substituted version removed that language and required the Department of Behavioral Health and Developmental Services to convene a group of stakeholders to study the use of Supported Decision-Making agreements in the Commonwealth, including making recommendations as to the use of Supported Decision-Making as a less restrictive alternative to the appointment of a guardian or conservator for an incapacitated person.</p> <p>Prohibits discrimination against people based on certain disabilities in the medical context of organ transplantation and identifies Supported Decision-Making services as auxiliary aids and services.</p> <p>Requested the Secretary of Health and Human Resources to study supported decision-making for individuals with intellectual and developmental disabilities.</p>

<p>Washington</p>	<p>Revises provisions and established procedures and requirements for dependent adult guardianships and conservatorships.</p> <p>Formally recognizes Supported Decision-Making as a less restrictive alternative to guardianship consistent with the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act.</p> <p>Prohibits discrimination against people based on certain disabilities in the medical context of organ transplantation and identifies SDM services as auxiliary aids and services.</p>
<p>Wisconsin</p>	<p>Codified Supported Decision-Making and a Supported Decision-Making Agreement Statutory form</p>