

Psychiatric Advance Directives and Supported Decision-Making: Preliminary Developments and Pilot Studies in California

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Abstract

The Saks Institute for Mental Health Law, Policy, and Ethics at USC Gould School of Law is engaged in an innovation planning project in California to pilot programs and test the feasibility of using psychiatric advance directives (PADs) within the supported decision-making (SDM) paradigm. The project is supported by California's Mental Health Services Oversight and Accountability Commission. This chapter provides an overview of the preliminary developments and pilot studies in the California PADs/SDM project. The project is a first-of-its-kind effort to explore the efficacy of the PADs/SDM paradigm across behavioral health county systems in the State of California. This chapter presents an overview of the pilot project and describes its research questions and implications, and ways in which the project and SDM paradigm embodies the principles of the United Nations Convention on the Rights of Persons with Disabilities.

Introduction

The Saks Institute for Mental Health Law, Policy, and Ethics at USC Gould School of Law¹ is engaged in an innovation planning project in California to pilot programs and test the feasibility of using psychiatric advance directives (PADs) within the

¹ The Saks Institute was founded in 2010 by Professor Elyn Saks as a think-tank dedicated to research among scholars, professionals, consumers, and policymakers. The institute studies issues at the intersection of mental health law and policy with a primary focus on improved treatment of, and quality of life for, people with mental illness.

supported decision-making (SDM) paradigm. The project is supported by California's Mental Health Services Oversight and Accountability Commission (MHSOAC). It is to develop a county-level and longitudinal PADs/SDM project to improve community mental health services for people with psychiatric disabilities at risk of involuntary care, criminal justice involvement, and involuntary hospitalization.²

SDM is a relatively new paradigm in the American context, and prominently in the context of the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).³ In particular, CRPD Article 12 affirms that persons with disabilities have the human right to recognition as persons before the law. States Parties to the CRPD must recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. They must take appropriate measures to provide access by persons with disabilities to the supports they may require in exercising their legal capacity, such as through SDM. Under Article 12, States Parties are to enact measures that relate to the exercise of legal capacity in accordance with international human rights law. These safeguards are to ensure that the exercise of legal capacity respects the rights, will, and preferences of the person, and are tailored to the person's circumstances.

The California Behavioral Health Departments of Fresno and Orange Counties Saks Institute project uses SDM paradigm in employing PADs. The Saks Institute's collaborative team includes the Burton Blatt Institute (BBI) at Syracuse University, Laurie Hallmark of Texas Rio Grande Legal Aid (TRLA), and other organizations and subject matter experts. The Saks Institute's partnership with BBI

² Staff Analysis: Fresno County, Psychiatric Advance Directive Supportive Decision Making (2019, on file with first author).

³ Blanck, P. & Martinis, J. (2015). "The right to make choices": National Resource Center for Supported Decision-Making, Inclusion, 3(1), 24–33.

includes development and implementation of a separate SDM pilot research study focused on people with psychiatric disabilities, specifically people with schizophrenia and bipolar disorder who have experienced psychosis.⁴

Professor Elyn Saks, Founder and Faculty Director of the Saks Institute, contributes as a person diagnosed with schizophrenia. Professor Saks' work has focused on autonomy and independent choice for persons with mental illness. Saks writes:

Not being allowed to make decisions for oneself is very degrading, painful, and disempowering. Patient choice is important even if the patient is impaired. Or even if we think he or she is making an obviously wrong decision. We allow people to make foolish or unwise decisions all the time.

Indeed, force is an unstable solution. If we encourage the patient to make her own decision, she is likely to be more committed going forward.⁵

This chapter provides an overview of the preliminary developments and pilot studies in the Saks/California PADs/SDM project. It is a first-of-its kind effort to explore the efficacy of the PADs/SDM paradigm across behavioral health county systems in the State of California. The next part, and thereafter the following part, present an overview of the project. The final part considers the pilot project's implications and next steps.

Saks Institute/California PADs/SDM Paradigm and Pilot Projects

⁴ Schnieders, C. (2019). Supported decision-making and people with psychiatric disabilities: Pioneering research at California's Saks Institute. *Impact* 32(1), 40–41

⁵ Saks, E. R. (2019). The power of making decisions. *Impact* 32(1), 42

Historically, people with psychiatric disabilities and other cognitive conditions have been segregated from society and subjected to lesser services, supports, and opportunities than their neurotypical peers.⁶ Because they also are often incorrectly viewed as “dangerous” or “less able,” countless individuals are unjustifiably institutionalized, faced undeserved levels of scrutiny from law enforcement, have high rates of unemployment, incarceration, and homelessness, and suffer loss of legal rights and social opportunities through conservatorship or guardianship.⁷ This situation has been the case both in the United States and globally, and it has been greatly exacerbated as a result of the COVID-19 pandemic.

The landmark Americans with Disabilities Act of 1990 (ADA) guarantees people with disabilities the “right to fully participate in all aspects of society.”⁸ A crucial component of the ADA, the “integration mandate,” requires state and local governments to provide supports and services to people with disabilities in integrated, community-based settings.⁹ As interpreted by the US Supreme Court in *Olmstead v. L.C.*,¹⁰ the mandate “aims to end centuries of US government-approved and assisted segregation, whether in state-run institutions or state-sponsored

⁶ See, e.g., Logue, L. M. & Blanck, P. (2018). *Heavy Laden: Union Veterans, Psychological Illness, and Suicide*, Cambridge University Press. Wood, E. (2005). History of Guardianship. In Quinn, M. J. *Guardianship of Adults: Achieving Justice, Autonomy, and Safety*. Springer Publishing Company.

⁷ Blanck, P. (2020). *Disability Law and Policy*. Foundation Press. Hallmark, L. & Martinis, J. (2019). Psychiatric advanced directives: The TRLA model in Texas. *Impact* 32(1), 43–44.

⁸ 42 U.S.C. § 12101(a)(1). Blanck, 2020.

⁹ 28 C.F.R. § 35.130(d)

¹⁰ *Olmstead v. L.C.*, ex rel. Zimring, 527 U.S. 581 (1999).

programs.”¹¹ The integration mandate also is consistent with the principles of the CRPD.

More than twenty years after Olmstead, and at the thirtieth anniversary of the ADA, significant numbers of people with psychiatric disabilities in California and across the United States – and globally – still have not received the social and economic opportunities promised by the ADA and other laws, and continue to cycle through hospitalization, criminal justice involvement, unemployment, and homelessness.¹² As mentioned, since enactment, the world has been watching the ADA. Other countries have been spurred on to follow its model, notably in the case of the CRPD as a seminal international initiative that reflects a new global era in disability human rights. The product of years of work by organizations of people with disabilities and disability experts from every continent, the CRPD was adopted by the United Nations General Assembly in 2006. It is an international treaty, protecting people with disabilities from discrimination. Like the ADA, the CRPD establishes a foundation for the protection and treatment of people with disabilities across a wide range of social and cultural activities. For instance, as mentioned, Article 12 is to ensure that States Parties enact measures that relate to the exercise of legal capacity by persons with disabilities.

In the spirit of the principles of the ADA and the CRPD, the Saks Institute project aims to create pilot programs among county-identified populations in the State of California to address and ameliorate these continuing disability rights

¹¹ Blanck, 2020; Hallmark & Martinis, 2019, 43.

¹² Hallmark & Martinis, 2019; See, also, e.g., Fresno County Mental Health Plan, 2017–18. Available at: www.co.fresno.ca.us/home/showdocument?id=34653; Monterey County Cultural Competency Plan Requirements, 2018/19 Update. Available at: www.co.monterey.ca.us/home/showdocument?id=84723.

problems. The objective is to enhance individual independence and self-determination for persons with psychiatric needs in areas such as education, housing, medical, employment, and financial empowerment. The aim is to understand and help implement ways for California counties, as models for others to follow, to improve access to personal, health, and daily life care, and improve the appropriateness and quality of care. It also aims to help in the preservation of each individual's life goals and preferences, and produce better self-determined outcomes for those with psychiatric disabilities who are at risk of involuntary commitment, homelessness, conservatorships, unnecessary hospitalizations, and involvement with the criminal justice systems at all stages of life.

Understandably, the COVID-19 pandemic has altered aspects of this project because county partners have refocused their primary efforts on the immediate threat from the virus to the disability and other vulnerable communities. Nevertheless, substantial progress is being made in collaboration with Fresno and Orange Counties, even during the difficult months of the pandemic.

In essence, the project is intended to model and assess strategies to use PADs under the SDM paradigm, to improve the effectiveness of community mental health services.¹³ With PADs, people with psychiatric disabilities use the SDM paradigm to identify and document their preferences for treatment, communication, and other issues to help them (or responders) in a crisis situation. This aspect of self-determination, and the right to make life choices, are key elements of a meaningful and independent life. Yet people with psychiatric disabilities are often

¹³ Staff Analysis – Fresno County June 2019. Available from first author, or at: https://mhsoac.ca.gov/sites/default/files/Fresno%20County_Inn%20Staff%20Analysis_PAD_062419_FINAL_ADA.pdf.

denied their right to make daily life choices about where they live and who they interact with, their finances, and their healthcare.¹⁴

One major objective of this project, in accord with the SDM paradigm and globally with the CRPD, is to empower individuals with mental health conditions to be more self-determined in all aspects of their lives. SDM is a paradigm in which people use trusted friends, family members, and professionals to help them understand the situations and choices they face, including risks and benefits, so they may make their own decisions.¹⁵ SDM is a means for increasing self-determination by encouraging and empowering people to make decisions about their lives to the maximum extent possible.¹⁶

PADs are a form of SDM and provide a means for documenting an individual's preferences in a legally recognized manner. The California project is among the first significant examinations as to the efficacy of PADs. PADs contain information as simple as medications or treatment modalities that have or have not worked, or as complex as specific steps that should be taken in a crisis. When the individuals choose, their PADs can be provided to law enforcement, crisis responders, medical personnel, and others so they are aware of the person's preferences.¹⁷ "PADs can inform responders and medical personnel that a person reacts poorly to Haldol or well to Zyprexa; has an attorney or supporter who should be contacted as soon as possible; or is a survivor of sexual assault who should be

¹⁴ Blanck, & Martinis, 2015.

¹⁵ Ibid.

¹⁶ Ibid. Shogren, K., Wehmeyer, M., Martinis, J., & Blanck, P. (2019). *Supported Decision-Making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life*, Cambridge University Press.

¹⁷ Hallmark & Martinis, 2019.

approached by a woman; or is helped by eye contact, which facilitates communication, or threatened by it, which causes a defensive response.”¹⁸

In using PADs, people with psychiatric disabilities also have the proactive opportunity to provide law enforcement, medical, and Crisis Intervention Team (CIT) personnel with information to help avoid or deescalate a potential crisis situation and provide informed better short-term treatment. This may lead CIT teams and other personnel to respond in a more positive and informed way, consistent with the person’s preferences and experiences, while reducing the likelihood that interactions will result in criminal charges or long-term, involuntary hospitalization. In addition, nonviolent crisis engagement may encourage people with psychiatric disabilities to view law enforcement and medical personnel as a helpful resource.¹⁹

In the United States, there is growing support for the use of PADs to encourage people to participate in and determine their care, even during times of limited decision-making capacity.²⁰ They are a recognized strategy to improve the quality of the caregiver-client relationship and to improve healthcare outcomes.²¹ More than half of US states have authorized some form of a PADs, and standard healthcare power of attorney statutes extend that authorization throughout the United States.²² The Joint Commission on the Accreditation of Healthcare Organizations, a

¹⁸ Ibid., 43.

¹⁹ Ibid.

²⁰ Staff Analysis – Fresno County June 2019, 2.

²¹ Swanson, J. W., Swartz, M. S., Elbogen, E. B., et al. (2006). Facilitated psychiatric advance directives: A randomized trial of an intervention to foster advance treatment planning among persons with severe mental illness. *American Journal of Psychiatry* 163(11), 1943–1951.

²² Appelbaum, P. S. (2004). Law and psychiatry: Psychiatric Advance Directives and the treatment of committed patients. *Psychiatric Services* 55(7), 751 – 763. California Probate Code Section 4800. [Link to California Probate Code Section 4800.](#)

major accrediting organization, recognizes the value of PADs for treatment decisions when an individual is unable to make decisions for herself or himself.²³

While PADs were first put into use in the United States in the 1990s, and have widespread support, research suggests their use is still limited by lack of awareness and significant challenges with implementation.²⁴ Some barriers involve working with individuals with persistent mental health needs to create the PADs, and sometimes the reluctance of clinicians to follow an advance directive.²⁵

PADs can enable people with mental illness to provide treating physicians with critical information in writing, in advance, that they may not be able to communicate during a psychotic episode or at the time of hospitalization.²⁶ Consequently, PADs may improve medical care by reducing “coercive crisis intervention,” facilitating doctor/patient communication and relationship development.²⁷

²³ JCAHO (2011). Revised Standard CTS.01.04.01. Care, Treatment, and Services. The Joint Commission, Behavioral Health Care Accreditation Program. Retrieved from: www.jointcommission.org/-/media/deprecated-unorganized/imported-assets/tjc/system-folders/topics-library/post_bhc_cts-chapter_20100630pdf.pdf?db=web&hash=199A99A175398868A527C942486EC96D.

²⁴ Staff Analysis – Fresno County June 2019, 2.

²⁵ SAMHSA (2019). Substance Abuse and Mental Health Services Administration: A Practical Guide to Psychiatric Advance Directives. Substance Abuse and Mental Health Services Administration. Retrieved from: www.samhsa.gov/sites/default/files/a_practical_guide_to_psychiatric_advance_directives.pdf.

²⁶ Hallmark & Martinis, 2019, 43

²⁷ Swanson, J. W., Swartz, M. S., Elbogen, E. B., et al. (2008). Psychiatric advance directives and reduction of coercive crisis interventions. *Journal of Mental Health*, 17(3), 255–267.

Saks Institute California Innovation Project Objectives

The project includes SDM as a strategy to support the creation and use of the PADs. SDM, as mentioned, is when people choose their supporters to help them understand the situations and choices they face to enhance their self-determination to the maximum extent possible.²⁸ Research finds that using SDM “may enhance feelings of self-empowerment and yield improved functional outcomes” for people with disabilities.²⁹ To that end, PADs and SDM are used to empower people with psychiatric and other disabilities to understand, make, and communicate decisions in all life spheres, including daily life, education, housing, medical treatment, employment, and financial empowerment.³⁰

The Saks Institute and its project partners outside of California have considerable experience designing, leading, implementing, and evaluating the impact of projects that empower people with disabilities to use PADs and SDM paradigm. Saks partner Laurie Hallmark, Special Projects Director at TRLA,³¹ is leading a project in Texas to empower people with psychiatric disabilities to create PADs that identify and state their preferences for treatment, communication, and other elements in a crisis situation.³² In this project, people with psychiatric

²⁸ Blanck & Martinis, 2015.

²⁹ Jeste, Eglit, Palmer, Martinis, Blanck, & Saks, 2018, 36.

³⁰ Hallmark & Martinis, 2019; Stoeltje, M. (2019). People with mental illness can get a say in their own treatment. *San Antonio Express-News*. Retrieved from: www.expressnews.com/news/local/article/People-with-mental-illness-can-get-a-say-in-their-13747403.php; Belluck, Pam (2018). Now mental health patients can specify their care before hallucinations or voices overwhelm them. *New York Times*. Retrieved from: www.nytimes.com/2018/12/03/health/psychiatric-advanced-directives.html. Swanson et al., 2008.

³¹ www.trla.org.

³² Hallmark & Martinis, 2019, 43

disabilities use SDM to draft individualized PADs to create a sustainable process for life and treatment decisions.³³ Project participants are encouraged and supported to identify their preferred treatments, support methods, supporters, medication, and providers. Once completed, the PADs are provided to law enforcement, crisis responders, medical personnel, and others so that they are aware of the person's preferences.³⁴

The predicted outcome of the Texas project is for PADs to enable participants to create their own legally recognized "rights document" with information critical to de-escalation and treatment. This is to help crisis personnel respond in a way consistent with the person's preferences and experiences – for example, in terms of medication usage and hospitalization choices and locations. PADs may include other critical information such as physical medical conditions, a statement of individual mental health care instructions and informed consent, medications for routine psychiatric treatment, preferences for emergency treatment, and powers of attorney for healthcare choices. The objective is to reduce the likelihood that interactions will result in criminal charges or long-term, involuntary hospitalization. In addition, nonviolent crisis engagement may encourage people with psychiatric disabilities to view law enforcement and medical personnel as a helpful resource.³⁵

The PADs may also enable increased collaboration and communication between people with psychiatric disabilities and their healthcare professionals and providers. Through their PADs, individuals with psychiatric disabilities "provide treating physicians with critical information in writing, in advance, that they may not

³³ Ibid., 44.

³⁴ Ibid., 43

³⁵ Ibid.

be able to communicate at the time of hospitalization.”³⁶ When implemented, the PADs help build relationships and trust between people with psychiatric disabilities and healthcare professionals.³⁷ Research shows that such enhanced relationships and communication leads to better health outcomes, more consistent medication management, and enhanced plan effectiveness and compliance, as well as increased job satisfaction and decreased burnout for healthcare professionals.³⁸

Beginning in 2016, the Saks Institute and its partner the BBI developed and is implementing a multisite pilot research project designed to examine the ways in which participants with diagnosed psychiatric disabilities, and in other studies persons with intellectual and developmental disabilities, use SDM to make decisions in multiple life areas; for example, in the areas of medical care and financial determinations, and to study the impact of SDM on their quality of life.³⁹ At three university sites in California and one in New York, the research team is partnering with people with psychiatric disabilities to educate them on the creation of SDM plans, “identifying areas in their life where they want support making decisions, the type of support they want, who will provide it, and how.”⁴⁰

Through their personal life plans, for instance in accord with the self-determination and legal capacity principles of the ADA and CRPD, project participants use SDM in areas including daily living, healthcare, employment, and

³⁶ Ibid.

³⁷ See, e.g., Swanson et al, 2008.

³⁸ See, e.g., Berg, S. (2017). Better communication with patients linked to less burnout. *American Medical Association*. Retrieved from: www.ama-assn.org/practice-management/physician-health/better-communication-patients-linked-less-burnout.

³⁹ Schnieders, 2019, 40–41.

⁴⁰ Ibid., 41.

financial management. As the participants implement their SDM plans, the Saks team is examining the impact SDM has on quality of life, including community integration and life satisfaction.⁴¹ The main prediction is that SDM usage will significantly increase participants' self-determination and enhance their life outcomes, including their ability to access and use community-based resources and services.

The Saks Institute's core project partner, BBI, is a cross-disability institute that has designed, implemented, and evaluated SDM programs in several states. BBI's projects are funded by national governmental agencies and designed to help people with intellectual and developmental disabilities link to, plan for, and implement SDM in daily life, education, housing, medical, employment, financial empowerment, and other life spheres. For example, in the "Successful Transition Program," BBI worked with students with disabilities, their families, and the state vocational rehabilitation agency and service providers to enhance student services and increase coordination and collaboration among the parties through the SDM paradigm.⁴²

BBI currently is undertaking a first-of-its-kind randomized control trial (RCT) experiment to test the efficacy of SDM over time for a large cohort of persons with intellectual and developmental disabilities. In that study, the "treatment" condition involves strategies for enhanced usage and training on SDM. The predicted outcome is that individuals in the experimental treatment condition, as compared to controls who received no enhanced training on SDM, over time will report greater self-determination and autonomy in daily life, and show a higher tendency to make

⁴¹ Ibid.

⁴² Martinis, J., Cassidy, K., Gustin, J., Nadeau, J., & Robinson, D. (2019). Creating a culture of coordinated support: Vermont's successful transition program. *Impact* 32(1), 19–21

decisions about their own lives with the support of others. As part of its projects, BBI and its partners have developed the Supported Decision-Making Inventory (SDMI). The SDMI is a validated survey instrument to assess the environment in which individuals make decisions. To date, the SDMI has been used with persons with intellectual and developmental disabilities, and in the future will be used in the Saks Institute projects with people with serious psychiatric disabilities.⁴³ The SDMI is not a mental or legal capacity instrument, but rather a means for an individual to assess his or her supports in the natural living environment.

The Saks Institute project partners also recognized that many state and local agencies serving people with disabilities often operate in “silos,” in which they typically are not aware of, or are not working collaboratively with, individuals and their providers of services.⁴⁴ To address this issue, and based on BBI’s prior studies, the Saks Institute focuses on educating individuals and service agencies to use SDM to develop individualized support plans that have cross-service provider system goals and supports based on the person’s abilities and interests.⁴⁵

California County Partners Engagement and Development of the Pilot Projects

⁴³ Shogren, K., Rifenbark, G., Wehmeyer, M., et al. (2020). Refining the Supported Decision Making Inventory, *Journal of Policy and Practice in Intellectual Disabilities*, <https://doi.org/10.1111/jppi.12335>.

⁴⁴ Martinis et al., 2019, 19.

⁴⁵ Ibid.

The Saks Institute's project team's direction and experience in creating, implementing, and analyzing programs using PADs and other forms of SDM, such as powers of attorney and forms of advanced directives, is consistent with the values and ongoing efforts of several California counties, including the Fresno County Adult System of Care Division, and the Monterey County Behavioral Health Board.⁴⁶ Like those programs, and others, the pilot project stresses self-determination by individuals with psychiatric disabilities and encourages coordination and collaboration among people, professionals, and service providers.

Fresno County, a county in central California, has been approved by MHSOAC as the lead county for a three-year project to pilot and implement the PAD/SDM innovation programs, with the Saks Institute project partners providing technical assistance and support. Orange County, near Los Angeles, has also committed to the innovation project. Modoc, which is a small county in northeastern California, has also expressed interest in joining the project.

For its part, Fresno County's project focuses on wellness and recovery throughout their county mental health system. The county trains in and uses the client-driven process of creating a Wellness Recovery Action Plan (WRAP) as part of crisis planning. WRAPs include aspects of SDM principles, such as the use of supporters to enhance self-determination. However, WRAPs lack legal standing with regard to the crisis system of care. Fresno County is proposing to deploy PADs to strengthen its commitment to client-driven planning and care provision, and to enhance the recovery focus of the county mental health system. The county's

⁴⁶ See, e.g., Fresno County Mental Health Plan, Outcomes Report, 2017-2018. Retrieved from: www.co.fresno.ca.us/home/showdocument?id=34653; Monterey County Behavioral Health Board, FY 2018/2019 Update: Monterey County Cultural Competency Plan Requirements. Retrieved from: www.co.monterey.ca.us/home/showdocument?id=84723.

objective is to develop a legal process for the design, deployment, and recognition of PADs to normalize formal recognition of a client's preferences and wishes during a mental health crisis.⁴⁷

The Saks Institute team has convened in-person and virtual meetings with the California counties to discuss potential activities and pilot programs, and to brainstorm new approaches. In Fresno County, for instance, one first topic discussed potential target groups of people with psychiatric disabilities to consider as the focus for Innovation Projects. The counties identified potential target groups, including individuals who are in or at risk of conservatorship, involuntary hospitalization, homelessness, and incarceration, as well as transition-aged foster youth who have been cycling into and out of hospitals. The COVID-19 pandemic response has necessarily taken priority for Fresno's Behavioral Health department activities in Central California. As a result, the size and scope of initial PAD/SDM pilot projects are being adjusted, beginning with a pilot program for individuals with psychiatric illness and who are currently homeless in the county.

The Saks Institute project team members have also held substantive virtual meetings with key personnel of Orange County's Behavioral Health department, as well as convening their community mental health stakeholders. The goals discussed included identifying barriers and challenges and legal implications. In addition, the goals are focused to evaluate the impact on participants and outcomes, and to understand use across participating counties and different target populations. Among the potential populations, as mentioned, the county recognized individuals living with serious psychiatric disabilities who are at risk of needing involuntary care, criminal justice involvement and involuntary hospitalization, and engagement with the

⁴⁷ Staff Analysis – Fresno County June 2019, 3.

Transitional Age Youth-Program of Assertive Community Treatment and Health Care Agency Correctional Health Services.

The California counties also examined with Saks Institute partners discussed how they may conduct education and outreach to the target groups about PADs/SDM. This discussion centered around the common and logical “entry points” for the PAD/SDM process in the county service systems, such as the peer-to-peer and legal services, hospitals, schools, law enforcement, and the criminal justice and conservatorship systems. The counties discussed when and how PADs/SDM may be introduced in those systems. They also identified critical junctures – intake, discharge planning, transition planning for Special Education, peer-to-peer and legal services, and when conducting outreach to people who are homeless – when it will be most effective to introduce PAD/SDM processes and encourage target group members to take part.

The California counties additionally examined ways that service systems may use SDM to create individualized PADs. The counties agreed that this process should include agencies and providers engaging in a person-centered process, that people may create and implement PADs based on their individual abilities, needs, interests, and informed choice. The Saks Institute project team members are collaborating with participating counties to schedule and conduct on-site and virtual technical assistance and training to help each county to develop policies and procedures that ensure their PAD process is the product of SDM and person-centered thinking. An essential element of this process will be cross-county collaboration in the development of their projects.

The counties further discussed ways to ensure that people are recognized as having PADs. For example, individuals in crisis may not be able to inform first responders that they have PADs. In those and other cases, county providers and responders will need mechanisms to make them aware the person has a PAD and ways to meaningfully review and follow it. This will help ensure effective, personalized care and build trusting relationships between people with psychiatric disabilities and their healthcare and other providers.

Throughout the collaborative discussions, it was acknowledged that the core issue of PAD recognition and use will be among the project's greatest challenges. During the project, we are developing processes and technologies to enhance acceptance of PADs by key stakeholders and providers, and most importantly by the individuals with psychiatric disabilities. To this end, the project team plans to enlist leading members from the technology arm of Painted Brain, which is a California-based mental health arts and tech organization that uses a peer model focused on recovery.⁴⁸ The Saks Institute and partners' "tech brainstorm" with Painted Brain's leadership, all of whom are individuals with psychiatric disabilities, was highly productive and planning is underway for collaboration on a consumer-driven model to enhance PAD recognition and use.

California County PADs Pilot Project Advancements and Barriers

⁴⁸ <https://paintedbrain.org/about/the-peer-run-business-model/>.

From meetings with the counties, initial ideas for advancement of the PADs project and next steps also included possible identification bracelets that people may wear voluntarily, alerting providers and responders they have a PAD (e.g., similar to the ROAD ID bracelets used by runners, bicyclists, and motorcyclists).⁴⁹ Other ideas for advancement included a secure online cloud-based or blockchain-type repository where people may voluntarily store copies of their PADs, and choose to allow providers and responders to access them as needed. In addition, the partners are discussing secure Quick Response (QR) codes that link to a person's PAD, which may be scanned to provide the information, while also encouraging people to keep physical and/or digital copies of their PADs on their person.

In project interviews, as mentioned, the counties reported that one barrier to adoption of PADs/SDM was the "silo" nature of service systems and providers. In such siloed systems, public and private providers often do not communicate or collaborate most effectively in the "voice" (will and preferences) of the individual. Consequently, each provider may have operating policies and procedures that conflict in practice with those of other providers. In such systems, PADs typically are of limited use because providers and first responders may not have (or may have conflicting) policies or practices to encourage people to create them, or mechanisms to recognize and respect them.

Accordingly, in the project the counties agreed that they would actively collaborate with the Saks Institute team partners and others to coordinate with public and private agencies and providers to work within existing systems. They also agreed to develop new, collaborative approaches that may empower people to

⁴⁹ www.roadid.com/.

create PADs, increase awareness when people have PADs, and enhance respect for the terms of people's PADs.

As the Saks Institute project progresses, next steps include working closely with each county to identify a roster of potential partners to target for outreach, training, and participation in this project. While the counties discussed the need to create unified, cross-system policies and procedures that encourage, empower, and respect PADs/SDM, it will be important to incorporate their service system policies and procedures, rather than only requiring partners to create new discrete policies and procedures.

After identifying potential public and private partners, the counties further brainstormed about ways to conduct outreach to other potential partners to provide important information about PADs/SDM and this project, and to encourage them to participate. The methods discussed included targeted educational and training material (that may be provided in-person, remotely, in writing, or online), and providing information on the research foundation and documented benefits. This also includes how PADs/SDM may be used as an alternative to conservatorship and guardianship, commitment, and involuntary treatment and as ways to reduce incarceration, homelessness, underemployment, and hospitalization. It also includes best practices, and development of case studies in accessible formats, in working with people to create and implement PADs through SDM, located on an accessible website hosted by the Saks Institute.

Finally, the counties discussed how they and the Saks Institute research team will evaluate and measure the efficacy of their Innovation Projects. As BBI is currently conducting in projects across the country, it will be necessary to determine

whether PADs/SDM have a positive and meaningful impact on reduced interactions with the criminal justice system, quality of life (using quantitative and qualitative measures) of target groups, and the quality of services and supports provided by and in the county. These issues also may be comparable across counties, and scaled across smaller and larger counties.

Next Steps and Research Questions to Examine

The Saks Institute project team in partnership with the California counties are currently identifying and examining potential quantitative and qualitative evaluative metrics, some previously validated by BBI, such as the SDMI, and others to be validated and tested. These measures include evaluations during crisis and other situations of the degree to which the PAD was effectively accessible, accessed, and used by the person, the provider (e.g., first responder, hospital, or doctor), or others such as family members or friends. Additionally, in what ways did use of the PAD increase the amount and quality of communication and collaboration between the person and his or her service providers.

It also will be necessary to examine the degree to which use of PADs/SDM increase the project participants' engagement with county supports and services, in areas such as housing, social services, supported employment, special education, adult education, and child welfare programs. Moreover, examination will occur as to the degree to which use of PADs/SDM increase participants' engagement in county supports and services. In addition, the project will consider whether use of PADs facilitates involvement and follow-through in their support plans.

Other research questions to examine include ways in which use of PADs/SDM enhance positive life and programmatic outcomes (community integration, housing stability, program completion, employment). In addition, the project will examine the degree to which use of PADs/SDM reduce people with psychiatric disabilities' criminal justice system involvement and recidivism; rates and length of hospitalization; or use and length of conservatorship. The rate and length of involuntary commitment and homelessness are important issues that the Saks Institute partners will explore in the future.

Conclusion: Mental Health and Decision Making, the ADA and the CRPD

As the Saks Institute project team and its partners in California continue this project with the support of MHSOAC, the efforts are proceeding cautiously, but with optimism. In accord with the guiding principles of the ADA and the CRPD, the longer-term objective is to enhance and extend human rights to all people with disabilities. The CRPD is spurring such change in domestic laws to address equal treatment of people with psychiatric disabilities. Like the ADA, the CRPD is a milestone in the advancement of the disability rights and inclusive principles to foster individual agency and self-determination in accord with the SDM paradigm.

The overarching objective of the Saks Institute portfolio of projects, in accordance with the principles of SDM and self-determination in the ADA and CRPD, is that these programs may lead to greater autonomy and reduced harm for individuals living with psychiatric disabilities. There currently is some uncertainty around the real-life use of PADs. However, the present project is one among many

innovation projects supported by California's Mental Health Services Act with the goal of increasing the quality of mental health services in the state through self-determination principles.⁵⁰ Despite the challenges in this undertaking, including the current COVID-19 pandemic, progress is being made in the United States and globally made to enhance the quality of life for people living with psychiatric disabilities.

The leadership of the California Fresno and Orange counties, in partnership with the Saks project team, is helping to better understand how development and implementation of PADs and the SDM paradigm can result in a more informed, person-centered approach to crisis situations. The belief is that this effort will lead to improved quality of life for those with psychiatric disabilities as active and self-determined individuals throughout their daily lives. The Saks Institute's efforts are meant to further such positive outcomes in California, nationally, and globally, towards the self-determination of persons with psychiatric disabilities in all aspects of life.

⁵⁰ MHSA'S Innovation Projects.

www.mhsoac.ca.gov/sites/default/files/documents/2018-06/MHSAOAC-IncubatorStakeholderHandout.pdf.