

THINKING AHEAD MATTERS

*Supporting and Improving Healthcare Decision-Making
and End-Of-Life Planning for People
with Intellectual and Developmental Disabilities*

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The Coalition for Compassionate Care of California is a statewide collaborative of organizations and individuals representing healthcare providers, assisted living facilities, nursing homes, hospices, consumers, state agencies and others working to increase access to palliative medicine and quality, compassionate end-of-life care.



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INTRODUCTION

*"Everyone must leave something behind when he dies.
A child or a book or a painting or a house or a wall built or a pair of shoes made."*

– Ray Bradbury, *Fahrenheit 451*

The experience of dying misses no one. We all eventually face the end of our life and the need to make decisions about health care during this period of time. If we do not actively plan for these decisions, others will make them for us. This begs important questions – do we wish to be at home or in a hospital or healthcare facility? Do we wish extraordinary measures to keep us breathing when the body no longer has the capacity? Will we be in pain, and will our pain be properly addressed? It takes deep wisdom to make the best decisions in such difficult circumstances, even for ourselves. To make these decisions for another is a sacred trust.

A recent Stanford University survey of nearly 1,100 physicians showed the overwhelming preferences of the people who see these choices played out every day. Over 88% stated that if they were terminally ill they would choose a do-not-resuscitate or "no code" status, allowing them to die without extraordinary interventions. "Doctors see a lot," said study author Dr. V.J. Periyakoil. Aggressive resuscitation attempts are likely to break an older patient's ribs but unlikely to restore their health or functioning¹ – after witnessing several, "you know too much and you're much more wary."²

Palliative care and end-of-life planning are healthcare strategies that empower people to have a say in these critical decisions, even when they are no longer able to voice their healthcare preferences. By means of an Advance Directive for healthcare decisions, people can and do make decisions for themselves. These can be general directions addressing

¹ Even when death is expected, resuscitation is performed on every person who dies in a healthcare facility without a Do Not Attempt Resuscitation order in place. 15% of people on whom it is performed survive to leave the hospital. Among those with multiple chronic illnesses, it is less than 5%. Drought, T. 2004. *Medical Decision Making for Publicly Conserved Individuals: Policy Recommendations*. p. 9. Retrieved on 6/7/14 from <http://www.scu.edu/ethics/practicing/focusareas/medical/conserved-patient/policy.html>.

² Span, Paula. New York Times, *The New Old Age: Caring and Coping, Do Not Resuscitate: What Young Doctors Would Choose* (5/20/14). Retrieved on 6/23/14 from http://newoldage.blogs.nytimes.com/2014/05/20/do-notresuscitate-what-young-doctors-would-choose/?_php=true&_type=blogs&_r=0.

cardiopulmonary resuscitation, medical interventions and artificially administered nutrition,³ or can specifically identify interventions the person does or does not wish (for example, a respirator, a feeding tube, transfusions, radiation or chemotherapy, or antibiotics. See Appendix A).⁴

Many people avoid planning for their own end-of-life care and do not exercise an active choice. Choices are then made for them. This is a serious outcome for anyone, but fundamentally, there is a developed mechanism for non-disabled persons to make their wishes, preferences and desires known. However, many people with developmental disabilities are denied the opportunity to exercise choice altogether. Our most vulnerable citizens may have even fewer opportunities than anyone else at the end of life, for a variety of complex reasons:

- Improved medical treatment for this population means people with developmental disabilities are experiencing a longer lifespan. Systems and strategies to support aging and end-of-life decision-making are under-prepared.
- Historical medical abuses of the population have resulted in important protections, but these same mechanisms can have the unintended consequence of dishonoring a person's desires at the end of life.
- The conservatorship process can be a complicating factor in end-of-life decision-making, especially for those individuals whose conservator is a Public Guardian.
- There is insufficient emphasis on supported decision-making for people with developmental disabilities throughout the lifespan, which is amplified when facing complex end-of-life situations.
- Lack of understanding of the disabled person's capacity to make his or her own choices and decisions, and the specific strategies and supports that assists them to do so, hampers courts, attorneys, conservators, healthcare providers and others with responsibility or involvement in end-of-life care.

In the absence of active support and respect for the disabled person's wishes, the most conservative and often most invasive healthcare decisions tend to prevail.

³ California Emergency Medical Services Authority, EMSA #111 B, *Physician Orders for Life-Sustaining Treatment (POLST)*, Effective 4/1/2011, p. 1. Retrieved on 6/23/14 from http://mydoctor.kaiserpermanente.org/ncal/Images/Polst_2011_tcm75-439385.pdf.

⁴ County of Los Angeles, Department of Mental Health, Office of the Public Guardian, *End-of-Life Request by Treating Physician*. Provides greater specificity than the standard POLST about the disabled person, his or her conditions, and a break-out list of interventions to accept or deny. This form does not appear to be online so is included as Appendix B.

Purpose of this Report

The Coalition for Compassionate Care of California (CCCC) is an organization promoting high-quality, compassionate care for all Californians who are seriously ill or approaching the end of life. In their work they have encountered circumstances where a person with a developmental disability was not supported to understand and exercise the choices s/he has, the results of healthcare decisions, the process and the consequences. These include troubling reports of disabled people who were cut off from friends and people they are close to at the end of their lives, had no choices in receiving painful and invasive procedures that undermined the quality of the end of their lives; have died in a hospital despite a preference to be at home; and even instances where the disabled person's wishes about where to be buried and who should receive their belongings after their death were disregarded.⁵

In some of these incidents, complex issues involved with the disabled person's conservatorship status complicated their end-of-life experiences. CCCC has undertaken this effort to try to understand more about conservatorship of people with developmental disabilities with an aim of fostering greater self-determination and empowerment of this population throughout life as well as at the end of life.

These are the questions considered in this report:

- What is the process of conservatorship for people with developmental disabilities in California?
- How large is the impact of conservatorship on healthcare decision-making for this population?
- What strategies would improve self-determination in healthcare decisions for people with developmental disabilities?

This paper considers these issues through the lens of people with developmental disabilities themselves as well as their advocates; including family members, attorneys, disability rights advocates, Regional Centers, bioethicists and providers who work closely with them. It relies on 21 qualitative interviews with a total of 22 key informants from these groups, as well as assembling background resources with strategies and policy recommendations on relevant topics that are intended to enhance the agency, dignity and choice of disabled individuals. The essential purpose is to strengthen the opportunity for the disabled person to make or

⁵ Relayed in personal communications by a variety of informants. See also the Coalition for Compassionate Care of California video library of resources for developmental disabilities. Retrieved 6/23/14 from <http://coalitionccc.org/tools-resources/video-library/>.

actively contribute to making decisions important to themselves, up to and including the end of life.

People with developmental disabilities are now aging; the benefit of long life is undoubtedly to be celebrated. And while end-of-life decision-making is a complicated area overall and issues around protection of vulnerable people exist for important reasons, there is no justification for people with disabilities to have less agency, choice or dignity in the experience of dying than others do. This includes respect for their wishes about health care interventions and where they want to spend their last days, as well as maintaining emotional attachments to the people that matter in their lives. And while there may be a rationale for conservative healthcare decisions that err on the side of protection, there is no justification for decisions based on fear of liability rather than the person's own choices and best interests, nor for dishonoring a person's wishes for their own burial or gifting of their possessions. These are the ways that all of us express our humanity and honor the people we love who are left behind.

The aging of people with intellectual and developmental disabilities (I/DD) presents challenges for systems to provide appropriate supports for the end of life and to ensure that the dignity, rights, choices and humanity of disabled people are fully included and respected. Improvements in this area will require multi-systemic changes in the way we think about the population's legal rights, health care and decision-making process.

BACKGROUND

People with a disability deserve the same rights as everyone.

– Petula Dvorak, Columnist, The Washington Post

California is widely regarded as having a model service system for people with intellectual and developmental disabilities (I/DD), although resource challenges over a number of years have strained the system and hampered to some degree its mission of providing treatment and habilitation services and supports in the least restrictive environment. (Habilitation services help a person learn, keep, or improve skills and functional abilities that may not be developing normally.) The system serves children and adults with an intellectual disability, cerebral palsy, epilepsy, autism and other conditions that are closely related to I/DD or require similar treatment; that originate before age 18; continue or are expected to continue indefinitely; and constitute a substantial disability for the person.⁶ The system was established under the Lanterman Developmental Disabilities Act of 1969 and the Early Intervention Services Act,⁷ and is organized around 21 Regional Centers and contracted providers serving a caseload of 275,000 consumers.⁸ There are also four state-operated Developmental Centers serving 1,100 individuals⁹ and the Canyon Springs Intermediate Care Facility, which serves up to 63 persons with challenging behavior issues. One facility – the Lanterman Developmental Center – is slated for closure no later than December 31, 2014.

The developmental disability (DD) system is organized around principles of an entitlement of access to services, integration of disabled persons into typical life activities and choices about where to live, education, employment, leisure and personal goals. Services for consumers over age 3 are provided through a person-centered Individual Program Plan (IPP) process that includes the consumer, family or representative, Regional Center staff and others chosen by the consumer, who gather to discuss the consumer's goals and strategies

⁶ California Welfare and Institutions Code, Section 4512. Retrieved on 6/29/14 from <http://law.onecle.com/california/welfare/4512.html>.

⁷ A useful overview of California's system is provided in The SCAN Foundation's Long-Term Care Fundamental brief, *California's Developmental Disabilities Service System*. Retrieved on 6/29/14 from <http://www.thescanfoundation.org/californias-developmental-disabilities-service-system>.

⁸ Department of Developmental Services. Regional Center Local Assistance 2014 May Revision of the 2014-15 Budget. Page D-1.1. Retrieved on 9/2/14 from http://www.dds.ca.gov/Budget/Docs/2014_2015RCMayRevision.pdf.

⁹ Ibid.

and services to achieve them. After first using “generic” resources such as Medi-Cal, Social Security, In-Home Supportive Services and other public or private resources the consumer is entitled to (for example, health insurance), the Regional Center then purchases the balance of supports the consumer needs to fulfill his or her IPP by contracting with community-based agencies which provide specialty services.¹⁰

As of March 2014, 9,701 or 4.12% of children and adults in the DD system lived in institutional settings including developmental centers, intermediate care facilities or skilled nursing facilities, and 1,111 (.66%) were classified as living in “other” setting, while the vast majority – 223,827 persons (95.21%) – lived in the community. Thirty-six percent (36.40%) are female and 63.60% are male. The population is similarly diverse as the rest of California, with approximately 36% identifying as white, 35% as Hispanic, 9% as African-American, 6% Asian, 2% Filipino, less than 1% as Native American or Polynesian and about 9% as other. Almost 25% of consumers in the DD system speak a primary language other than English. Over twenty percent (20%) of California’s Regional Center consumers are age 42 and up, with 9,463 who are age 62 and older.¹¹

Aging of the Population

People with developmental disabilities are living longer, and systems and services are underprepared to assist them with the aging process. In the 1940’s people with I/DD had a life expectancy of 20-plus years; in the 1960’s this improved by ten years.¹² Today, with the reduction in institutionalization and over-crowded, understaffed and under-funded conditions,¹³ people with I/DD have a life expectancy near that of other adults, with an average life of 65 years compared to 70 in the general population.¹⁴ This is due to improved health care, social services, recreation and physical activities, good nutrition and personal,

¹⁰ Ibid.

¹¹ State of California, Department of Developmental Services. *Quarterly Consumer Characteristics Report* http://www.dds.ca.gov/FactsStats/docs/QR/March2014_Quarterly.pdf.

¹² Karp, G. 1999, *Aging and Disability, Patient-Centered Guides*, Chapter 4 of *Life on Wheels*, OReilly & Associates, Inc. Retrieved on 7/8/14 from <http://www.patientcenters.com/wheels/news/aging.html>.

¹³ Kennedy, D. 2006, Encouraging Quality of Life for Aging Persons who have Developmental Disabilities, *Counselling, Psychotherapy, and Health*, 2(1), 62-67, April 2006. Retrieved on 7/8/14 from http://www.cphjournal.com/archive_journals/V2_11_Kennedy_62-67_04_06.pdf.

¹⁴Janicki MP, Dalton AJ, Henderson CM & Davidson PW (1999). Mortality and morbidity among older adults with

intellectual disability: health services considerations. *Disability and Rehabilitation*, 21, 284-294. Retrieved on 7/8/14 from <http://infoassist.panpha.org/docushare/dsweb/Get/Document-13011/DISABILITY%20AND%20REHABILITATION.pdf>.

spiritual, educational and employment opportunities.¹⁵ Similar to other adults, women live longer. People with Down Syndrome die on average ten years earlier, at age 56. Causes of death among those with I/DD mirror the age-related illnesses of the general population, such as cancer, heart disease and chronic lung disease.¹⁶ In the year 2000, about 500,000 people, or 12% of all people with I/DD nationally, were over the age of 65.¹⁷ The number of adults who are age 60 and over is projected to reach nearly 1.2 million by 2030.¹⁸

Individuals with I/DD experience normal aging processes including reductions in functional vision, hearing and balance. In addition, aging among people with I/DD is affected by their unique disabilities, chronic conditions and severity of conditions. Age-related changes may occur earlier. Obesity and osteoporosis appear to be more prevalent,¹⁹ and individuals with Down Syndrome may experience adaptive skill losses earlier than others. People with I/DD have often been subject to medication regimes throughout their lives, and the addition of other medications for symptoms related to aging can cause extreme complications in psychopharmacology. There also appears to be an “intimate link” between the genetic code controlling Alzheimer’s disease and that controlling Down Syndrome, so these individuals are at high risk for developing dementia of the Alzheimer’s type.²⁰

There is a high incidence of depression among all aging persons, and people with I/DD are particularly vulnerable. Having struggled to achieve independence, people may be subject to severe depression as they lose functional capacity and experience greater dependence on others. Those with cognitive issues or lacking the ability to communicate their needs, wants or feelings may experience frustration, potentially leading to acting out behaviors or intensification of pre-existing behavioral problems.²¹ Geriatric specialists, healthcare providers and systems of care management need to be informed about these issues and how

¹⁵ Kennedy, D. 2006.

¹⁶ Ellison, N. and Rosielle, D. *Palliative Care for Adults with Developmental Disabilities. Fast Facts and Concepts*. November 2007; #192. Retrieved on 7/8/14 from <http://www.eperc.mcw.edu/FileLibrary/User/jrehm/fastfactpdfs/Concept192.pdf>.

¹⁷ Minde, J. and Friedman, A. 2000. *The Graying of Disabled America*. The National Special Needs Network, Inc. Retrieved on 6/28/14 from http://www.nsn.com/graying_of_disabled_america.htm.

¹⁸ Heller, T. et al (Eds.) (Winter 2010) *Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities*, 23(1). Minneapolis: University of Minnesota, Institute on Community Integration. Retrieved on 6/28/14 from <http://ici.umn.edu/products/impact/231/>.

¹⁹ Factor, A.R. 1997. *Growing Older with a Developmental Disability: Physical and Cognitive Changes and Their Implications*. Chicago: Rehabilitation Research and Training Center on Aging with Mental Retardation, University of Illinois at Chicago. Retrieved on 6/28/14 from https://depts.washington.edu/aedd/growing_older_dd_Factor.html.

²⁰ Minde, J. and Friedman, A. 2000.

²¹ Ibid.

to assist people with disabilities with life transitions related to aging. Multidisciplinary approaches, improved training of healthcare professionals and development of relevant models of care are important to meet this population's needs.²²

These demographic changes are happening in the context of the aging boom in all populations, as well as the aging of family caregivers. Nationally, over 75% of people with I/DD live with their families, and more than 25% of family caregivers are over the age of 60.²³ Jeffrey Minde has written in *The Graying of Disabled America* that, "For the first time in human history, persons with developmental disabilities are outliving their parents who have historically always functioned as their primary caregivers."²⁴ In some cases, disabled adults are themselves become responsible for caregiving and end-of-life decision-making for their aging parents. This significant shift indicates a need for care and attention by systems designed to serve people with I/DD, to appropriately support the population's needs as they themselves age without the benefit of their primary support systems.

Encouraging quality of life for aging people with I/DD will require a dual focus on aging and disability services. There is a need to disseminate information about age-related health issues and to improve preventive and surveillance strategies across the lifespan for people with I/DD, including targeted health education programs, appropriate screening and community health promotion.²⁵ People will need home modifications, access to assistive technology, greater access to community services and more support for aging at home. Ageism is a factor for all, and is likely to be even more apparent for aging people with I/DD. It is important for caregivers and social educators to understand the context of what people with I/DD have experienced in relationship to that of the dominant culture in order to understand the additional impacts of aging.²⁶

As they age, people with I/DD seek the same outcomes as neurotypical individuals: maintaining their physical and mental health and functioning as independently as possible, actively engaging with life through friendships, contributions to society, and meaningful participation in community life.²⁷ Appropriate planning and supports are necessary to support people with I/DD as they age. Successful aging for everyone requires knowledge about the aging process as well as commitment to maintaining one's quality of life – and

²² Kennedy, D. 2006.

²³ Heller, T. et al (Eds.) Winter 2010.

²⁴ Minde, J. and Friedman, A. 2000. p. 1.

²⁵ Ibid.

²⁶ Kennedy, D. 2006.

²⁷ Heller, T. et al (Eds.) Winter 2010.

people with I/DD will need guidance to acquire the knowledge and skills they need to age well.²⁸

A Pro-Disability Philosophy

The aging of the I/DD population has broad implications in addition to end-of-life planning, including the needs of planning for retirement, assistive technology, home modifications and other supports for healthy aging. These life transitions must be grounded in a pro-disability attitude. End-of-life planning in particular must be based on the understanding that each person has the right to life despite any level of disability, and people with disabilities are equally entitled to pursue curative interventions as people without chronic disabilities. Clinicians should be aware of their own lack of experience with the population and biases in assessing quality of life, understanding that people with disabilities are able to lead fulfilling lives that are cherished by themselves and those who love them.²⁹ Surrogate healthcare decisions, when needed, should be made by caregivers who know the patient well and attempt to view quality of life from the patient's perspective. King, Janicki et al of the Last Passages Advisory Council have written on the philosophy and recommendations for end-of-life care for people with I/DD,³⁰ outlining a number of key principles:

- Healthcare providers must recognize the difference between disability management and prolonging the end of life; the distinction between living with a chronic disability and terminal illness.
- Exercising healthcare decisions and planning for end-of-life care should be an on-going activity in a person's life that begins well in advance of a terminal illness.
- Conservators and substituted decision-makers should be encouraged to make decisions in advance of a critical incident in order to make sound decisions.
- For decision-making to be meaningful, individuals and their families must be provided with the training and support they need to make decisions and choices.
- People with I/DD should not be excluded from understanding death and the opportunity to participate in the rituals of death, such as attending funerals, visiting a

²⁸ Ontario Partnership on Aging & Developmental Disabilities. 2007. *Caregiver Support: Aging Issues*. Retrieved on 6/28/14 from <http://www.opadd.on.ca/Caregiver/agingissues.htm>.

²⁹ Ellison, N. and Rosielle, D. November 2007; #193.

³⁰ King, A., Janicki, M. et al. 2005. *End-of-life Care for People with Developmental Disabilities: Philosophy and Recommendations*. University at Albany Center for Excellence in Aging Services. Retrieved on 6/28/14 from <http://www.albany.edu/aging/lastpassages/lp-philosophy.htm>.

cemetery where someone loved is buried, or planning and participating in a memorial service for a friend or relative.

- People with I/DD should be taught skills associated with comforting and recognizing and dealing with grief.
- People with I/DD must have access to the full range of end-of-life care options available to the general community, including the right to high-quality health care, palliative care, hospice, home health, family support and spiritual comfort.
- People with I/DD must have their pain recognized and treated appropriately; providers need specialized pain management training for the population, and family members and providers should communicate with physicians about an individual's pain, especially when the person is not fully able to communicate.
- The right to die at home should include supportive living residences and group homes.

LEGAL ISSUES

“When you’re talking about a conservatorship you’re talking about limiting somebody’s civil rights. All options should be explored before considering that alternative.”

– Stephen Dale, Attorney

Prior to the late 1970’s, conservatorship of people with intellectual and developmental disabilities was the norm, a widespread practice that was done swiftly with little due process. Securing a conservatorship cost about \$50 and included neither a hearing nor legal notification.³¹ The process of conservatorship of people with I/DD was the same as that for general conservatorship, and was often in the context of institutionalization, which was viewed as the standard of care for the population.

One of the profound consequences of the wholesale appropriation of people’s rights was on medical decision-making, leading to widespread involuntary sterilization. In 1909 California passed the first sterilization law, which was expanded in 1913 and 1917 to include a wider range of people, particularly those with disabilities. In 1927 the United States Supreme Court decision *Buck v. Bell* upheld the practice of forced sterilization, and between 1909 - 1964, 20,108 people were recorded as being sterilized in California. This is thought to be a conservative estimate. Sixty percent (60%) of these were deemed mentally ill and 35% were considered mentally “deficient.”³²

There was no legal mechanism to challenge a sterilization order, no written notification of the person or family, and no hearing process. Sonoma State Home performed more sterilizations on people with mental disabilities than any other institution in the world prior to 1942, and in 1950 alone sterilized 5,500 patients.³³ These involuntary surgeries were done on the authorization of the Board of Trustees and a clinical psychologist. Researchers report

³¹ Dale, Stephen. Limited Conservatorships for Persons with Developmental Disabilities. Retrieved on 5/20/14 from http://m.youtube.com/watch?index=1&list=UUdl0qBR1ye456XoU_Ok8V6g&feature=plcp&v=qUskbE6kDS0.

³² Kaelber, L. 2012. *Eugenics: Compulsory Sterilization in 50 American States: California*. University of Vermont. Retrieved on 7/13/14 from <http://www.uvm.edu/~lkaelber/eugenics/>.

³³ Ibid.

that Sonoma also conducted dangerous tests and trials on patients into the 1960's.³⁴ Forced sterilization became illegal in California in 1979; today it requires a court order for a person with I/DD to be sterilized.³⁵

By the 1970's pressure against these conditions and against institutionalization in general precipitated change, led by families of people with I/DD. They advocated for the passage of the Lanterman Act in 1969 to establish a system of services that would provide for independence and support for living in the community. In the late 1970's a series of reforms was instituted to the conservatorship process, intended to create due process and protect the rights of conserved persons. In 1977 the position of court investigator was created, and courts received authority to appoint an attorney to represent proposed conservatees.³⁶ In 1980, California established the "Limited Conservatorship" specifically for adults with I/DD.

Overview of Conservatorships

There are several types of conservatorship in California: conservatorships of *the person*, and in a separate category, conservatorships of *the estate*. Among conservatorships of the person, there are four types.³⁷ General conservatorship is aimed at adults who cannot take care of themselves;³⁸ Limited Conservatorship for adults with I/DD; and Lanterman-Petris-Short (LPS) conservatorships for involuntary psychiatric care, which can only be initiated by a local government agency. Temporary conservatorships of up to 30 days are available for emergency situations, but these have become increasingly rare as court funding issues have created difficulties in accessing them. General, limited and temporary conservatorships are based in the California Probate code ("Probate conservatorships.") In California, "guardianship" refers to legal responsibility for a minor.

³⁴ Ibid.

³⁵ California Probate Code, Section 1960 et seq. Retrieved on 9/2/14 from

<http://www.leginfo.ca.gov/cgi-bin/displaycode?section=prob&group=01001-02000&file=1950-1969>.

³⁶ Coleman, T. 2014. *Justice Denied: How California's Limited Conservatorship System Is Failing to Protect the Rights of People with Developmental Disabilities*. p. 10. Retrieved on 7/12/14 from

<http://www.disabilityandabuse.org/conferences/justice-denied.pdf>.

³⁷ Benitez, R. 2003. *The Ins and Outs of Conservatorships in California*. California Association of Marriage and Family Counselors. Retrieved on 7/13/14 from

http://www.camft.org/ScriptContent/CAMFTArticles/Legal_Issues/Conservatorships.htm.

³⁸ General Probate conservators may also seek special "dementia powers" which allow them to make decisions that would not normally be allowed: to place the conservatee in a locked facility and to authorize psychotropic medications for treatment of dementia. California Advocates for Nursing Home Reform. 2013. *Probate Conservatorships in California*. Retrieved on 7/22/14 from

http://www.canhr.org/factsheets/legal_fs/html/fs_ProbateConservatorship.htm.

Figure 1: Types of Conservatorship in California

Conservatorship of the Person	Conservatorship of the Estate
General Conservatorship of the Person	General Conservatorship of the Estate
Limited Conservatorship of the Person	Limited Conservatorship of the Estate
Temporary Conservatorship of the Person	
LPS Conservatorship for Psychiatric Care	

Many adults with I/DD do not have an estate, having income consisting only of Social Security Supplemental Security Income (SSI), which is normally managed by a representative payee. Assets held in the disabled person’s name can be disqualifying for public benefits such as SSI, Medi-Cal, and In-Home Supportive Services. In situations where adults with disabilities inherit money, it is common to establish a Special Needs Trust that can hold assets and distribute funds for essential needs, without interfering with qualification for public benefits. Sometimes conservatorships of the estate are granted even when the person has no assets.

Although Limited Conservatorships were designed and intended to be used for persons with I/DD, this type of conservatorship is not required in law for the population. A Regional Center reports that sometimes general conservatorships are initiated for their clients, creating confusion and requiring complex advocacy to inform the courts that the conservatorship is more appropriately of the limited type.³⁹ Other informants note that some counties prefer a general conservatorship because it does not require a regional center report and the appointment of counsel for the proposed conservatee, which has financial implications for the court. A strong recommendation from several informants was that California law should require that any client of a Regional Center should qualify only for a Limited Conservatorship, rather than a general conservatorship.

Limited Conservatorship of the Person

While all conservatorships restrict personal liberties and take away fundamental rights, the intention of the Limited Conservatorship is to be highly individualized. According to

³⁹ Use of general conservatorship for persons with I/DD varies significantly from county-to-county. Informants in Los Angeles state that it is rarely used, while an informant from Alta Regional Center in northern California estimates that up to 75% of clients are under a general rather than a Limited Conservatorship.

conservatorship attorney Stephen Dale, Limited Conservatorships are intended to give “just the right amount of powers – not too much, not too little.” While the general conservatorship process begins with an assumption that all powers will be given and the judge may reserve some rights as the process unfolds, Limited Conservatorship does not presume the disabled person is incompetent. Limited Conservatorships are designed to help persons with I/DD lead more independent, productive and normal lives, and the disabled person retains all legal and civil rights except for those the court specifically grants to the conservator.⁴⁰ It requires consideration of the person’s abilities in seven fundamental areas, and awards the conservator rights to just those powers where the person needs assistance.

The seven powers of Limited Conservatorship are:

- The right to select the residence of the disabled person;
- The right to access confidential records and papers;
- The right to consent or withhold consent for marriage;
- The right to contract;
- The right to give or withhold medical consent;
- The right to control social and sexual contacts;
- The right to make decisions concerning the disabled person’s education.

In addition, certain powers are restricted. A limited conservator may not commit a person to a locked psychiatric facility without a separate LPS conservatorship, may not authorize psychosurgery (lobotomy), treatment with experimental drugs, electroshock treatment, abortion, permanent sterilization (without a court order) or assisted suicide or euthanasia.⁴¹

The “mere diagnosis” of a mental or physical disorder is not enough to establish “unsound mind or lack of capacity to do a certain act.”⁴² Capacity to give or refuse informed consent for medical treatment, for example, means the person can respond knowingly and intelligently to queries about the proposed treatment, can participate in the treatment process through rational thought, and can also understand the fundamentals of medical treatment. This includes understanding the nature and seriousness of the illness and recommended

⁴⁰ Ross, B. 2002. *Conservatorship Litigation And Lawyer Liability: A Guide Through The Maze*. Stetson Law Review. Retrieved on 7/16/14 from <http://www.stetson.edu/law/lawreview/media/conservatorship-litigation-and-lawyer-liability-a-guide-through-the-maze.pdf>.

⁴¹ California Probate Code 2356. Retrieved on 9/3/14 from <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=prob&group=02001-03000&file=2350-2360>.

⁴² California Probate Code 811(d). Retrieved on 7/16/14 from <http://law.onecle.com/california/probate/811.html>.

treatment, the probable degree and benefits of treatment, the consequences of lack of treatment and the nature, risks and benefits of alternatives.⁴³

Any adult may petition to establish a Limited Conservatorship, including the spouse of the disabled person, a relative, any interested public officer or employee of an interested public agency, or any other interested person or friend. There is a natural preference for a family member, but it can be anyone except for the supervising healthcare provider or an employee of the healthcare institution or facility where the person is receiving care, unless that person is a relative.⁴⁴ A Public Guardian may serve as a limited conservator if there is no other available, although some counties preclude the Public Guardian's office from doing Limited Conservatorships because of resource constraints. Co-conservators may also be appointed. When there are two conservators, decisions must be made by consensus, and when there are more than two, decisions are made by majority. The job of a limited conservator is to secure all needed habilitation or treatment, medical and psychological services, education, training, social and vocational opportunities and to assist the disabled person to develop maximum self-reliance and independence in the least restrictive manner.⁴⁵

Limited Conservatorships involve a number of discrete steps. A recent report, *Justice Denied: How California's Limited Conservatorship System is Failing to Protect the Rights of People with Developmental Disabilities* by the Disability & Abuse Project of Spectrum Institute,⁴⁶ provides a general outline of the transactions associated with Limited Conservatorships. It is important to note that approved procedures vary in each jurisdiction based on local court processes, but this is an outline of an ideal process:

- A parent, family member or interested party may file a petition for Limited Conservatorship with the Probate Court. A copy of the petition is given to the person with a disability, close relatives and the Regional Center.
- The court will appoint a court investigator, who is an employee of the court. The investigator visits the home of the disabled person and conducts an in-person interview, reviews psychological and medical records and determines the level of disability and the extent to which the person can make major life decisions.

⁴³ California Probate Code 1881. Retrieved on 9/3/14 from <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=prob&group=01001-02000&file=1880-1898>.

⁴⁴ Ibid.

⁴⁵ Benitez, R. 2003.

⁴⁶ Retrieved on 7/12/14 from <http://www.disabilityandabuse.org/conferences/justice-denied.pdf>.

- The investigator files a confidential report with the court and serves a copy on parties to the case. Any interested party, such as another family member, can object to the need for a conservatorship or to the assessment of the level of the disabled person's incapacity.
- The Regional Center is notified that the client is the subject of a Limited Conservatorship proceeding. The law requires the Regional Center to assess the capacities of the client to make major life decisions and to make a confidential report to the court, and to file this report within 30 days.⁴⁷
- The court appoints a private attorney to represent the disabled person. Proposed conservatees are constitutionally entitled to a court-appointed attorney if they cannot afford to hire one.
- The person requesting to be conservator files paperwork with the court acknowledging the duties of a conservator and the rights of the disabled person. The court investigator, the disabled person's attorney and the Regional Center all file reports with the court, which are served on the parties to the case.
- The opinion of the proposed conservatee is sought. If s/he has an opinion about who the conservator should be, the court considers that.⁴⁸
- Once all paperwork has been filed, the proposed conservator and the disabled person appear before the judge. This usually occurs 60 – 90 days after the petition is filed. The person with a disability must attend unless a doctor certifies that s/he cannot because of medical reasons.⁴⁹ The judge may ask questions of the person, and then enters an order granting the petition. A party who disagrees with the judgment may file a notice of appeal.
- Unless someone has filed an objection requesting a hearing, the case is ready for resolution. The Probate Court is a "Court of Equity," a court where a commonsense decision prevails in a more informal environment than that of a criminal court.⁵⁰
- In the case of an objection, the judge hears the contested issues and then enters a judgment. One review of court records in Los Angeles found that in that county, objections are filed in only 2% of cases and appeals are virtually non-existent.

⁴⁷ California Probate Code Section 1827.5. Retrieved on 7/13/14 from <http://www.saclaw.org/pages/conservatorship.aspx>.

⁴⁸ Dale, Stephen. 2008. Limited Conservatorship Workshop. Retrieved on 5/20/14 from <https://www.youtube.com/watch?v=eAnXbJDR-nc&feature=youtu.be>.

⁴⁹ Ibid.

⁵⁰ Ibid.

- One year later, the court investigator visits the conservatee to check on his or her welfare, filing a confidential annual report with the court. Thereafter, the court investigator is required to conduct reviews and file a confidential biennial report. The Limited Conservatorship remains “open” for the conservatee’s lifetime.
- In any open case, the conservatee or conservator can file a supplemental petition at any time, and anyone can send a letter to the judge if they feel the conservatee is being mistreated. If a supplemental petition or complaint is filed, the court can order another investigation or can appoint an attorney to represent the conservatee. A hearing can be held and an appeal can be filed.⁵¹

How Many DDS Consumers Are Conserved and Who Are Their Conservators?

In considering the extent of conservatorship of adults with I/DD in California and the impact of conservatorship on healthcare decision-making, it is useful to quantify the number of persons under conservatorship, and who serves as conservators. The California Department of Developmental Services provides the following information regarding the legal status of consumers in its system:

Figure 2: Legal Status of DDS Consumers

Legal Status	Age 18+ yrs
No Conservator	100,979
Parent or Relative	25,500
Has Conservator - not DDS	11,597
Has Conservator - not DDS (Public Guardian)	871
Other (Has Conservator, Such as Private Conservator)	791
Ward of Court	522
Director of DDS	511
Unknown	344
Regional Center Director	168
Miscoded	1
TOTAL ADULT CLIENTS	141,284

Source: California Department of Developmental Services, July 2014

⁵¹ With the exception of separately footnoted items above, this section is excerpted from: Coleman, T. 2014. pp. 12-14.

According to this data, the vast majority of adults with I/DD in California are not under conservatorship (100,979 persons, or 71%). A parent or relative serves as conservator for 18%, and another 8% have a non-DDS, non-relative conservator. The data specifies that 871 people statewide have a Public Guardian as conservator and a small number are a ward of the Court, or have DDS or a Regional Center director serving as their conservator.

There are limitations to this data. DDS relies on self-report of the Regional Centers and is not able to definitively confirm that statewide the data are being uniformly reported.⁵² For example, they are not able to distinguish the difference Regional Centers are reporting between the category “Has Conservator – Not DDS” and “Other (Has Conservator, Such as Private Conservator).” They also allow that despite the fact that there is a discrete category for “Public Guardian,” there may be additional clients who are served by a Public Guardian but who are being reported in another category. Finally, they do not have data on the number of clients who have both a Limited Conservatorship and an LPS conservatorship for psychiatric treatment, information that would red-flag a potentially vulnerable subset of the population.

Nevertheless, several useful trends can be discerned. A large majority of adults with I/DD in California retain their civil rights to make decisions, presumably relying on supportive decision-making when needed. Predictably, among those under conservatorship, the largest category has a relative who serves as conservator. And a small number of people have a non-relative conservator, Public Guardian or DDS serving as their conservator. These findings can be of assistance in focusing public policy efforts.

Critiques of the Limited Conservatorship Process

Attention has begun to focus on Limited Conservatorships and how they operate, raising concerns that they do not function as intended. There was strong feedback from informants involved in conservatorship about the negative impact of California’s diminished funding of both the courts and the Regional Centers. One described the court-funding crisis in particular as resulting in “chaos” in court processes. Several attorneys also believe that cuts to Regional Centers have diminished the assessment of the disabled person’s capacities. They state that Regional Center assessments have become less individualized and more pro-forma,⁵³ with

⁵² State staff, California Department of Developmental Services, personal communication, 7/15/14.

⁵³ Attorneys felt that courts often disregard Regional Center assessments because they feel that these reports are “canned” rather than personalized. However, Disability Rights California (DRC) states that some courts, particularly in the Los Angeles area, disregard Regional Center reports even when they are individualized and high-value. The seven Los Angeles Regional Center Directors have met with the Probate court about the

boilerplate language submitted in many cases rather than accurate personalized reporting on client capacity in each of the seven powers. Other informants identify a lack of training and knowledge of the population amongst attorneys and court officials as a complicating factor. And while there are differences of opinion about the location of the dysfunction and how it is evidenced within the system, there is widespread agreement that lack of proper oversight and remediation is a significant problem in cases where conservatorships are bad. Informants report that this is a significant problem that is hard to remedy, with serious consequences for vulnerable conservatees. All informants saw funding cuts as a core contributor to these problems and stated that they cannot be resolved without an appropriate level of funding for both systems.

Informants also provided feedback that there are many instances where the ideal process and legal requirements are not implemented. Copies of the petition are not always provided to the person with a disability and their close relatives. One informant reports never having seen a court investigator review psychological and medical records as part of the process. One stated that disabled persons are frequently not in attendance at the court hearing even though they are medically able to attend, and proposed conservatees are rarely consulted about who should be appointed as conservator. Informants noted that annual or biennial in-person visits to the conservatee to check on their welfare only occur rarely, and reported that the initial in-person interview with the court investigator is often conducted without privacy, in the presence of the parent or potential conservator, thereby making it difficult for the disabled person to provide candid information.

In addition, there was concern expressed about conflict of interest issues that may arise when DDS or a Regional Center director serve as conservator under the process set forth in Health & Safety Code § 416 *et seq.*⁵⁴ When DDS is appointed conservator, the Regional Center is delegated to carry out these duties. However, the Regional Center is also the funder or purchaser of services for the disabled person. When a parent or other individual serves as conservator, one of the responsibilities is to attend the IPP process and advocate and negotiate for the services that the disabled person needs. Examples of services that might be negotiated in the IPP process include applied behavioral analysis, anesthetic dentistry, occupational or speech therapy, or other types of therapy. When the Regional Center serves

tendency to “rubber stamp” conservatorships regardless of the content of Regional Center reports, but DRC sees no discernible changes in court process.

⁵⁴ California Health & Safety Code Section 416 *et seq.* Retrieved on 9/3/14 from http://leginfo.legislature.ca.gov/faces/codes_displayText.xhtml?lawCode=HSC&division=1.&title=&part=1.&chapter=2.&article=7.5.

the dual role of conservator as well as the payor for services, there is an inherent conflict of interest that does not necessarily serve the interests of the disabled person and fully meet his or her needs.

The *Justice Denied* report outlines some additional ways that problems have manifested in the Limited Conservatorship process.⁵⁵ Utilizing a review of Limited Conservatorship cases in the Los Angeles Superior Court, the report sees that the following problems have occurred.

First, there are too few court investigators to carry out the work. The law requires a court investigator to conduct investigations on all initial petitions, conduct an annual review one year later and a biennial investigation thereafter. One informant has called this investigation the most important information in the Limited Conservatorship process. If there is a report of suspected abuse of a conservatee, that should also prompt an investigation. However, court investigators are paid by the court directly. Due to ongoing court funding constraints, an overwhelming caseload and consequent understaffing, the court investigator report appears to be frequently *waived* in Los Angeles, with substitution of the Regional Center report or the report of the attorney who serves as the conservatee's court-appointed attorney, in place of the court investigator report.⁵⁶

This approach diminishes the impartial investigation of the circumstances and appropriateness of the conservatorship, and also creates a conflict-of-interest for the court-appointed attorney, who is ethically obligated to represent the rights of the client rather than the interests of the court. As a result:

"The practice of waiving reports from court investigators, and substituting PVP [attorney] reports instead, has the effect of turning attorneys who should be advocates into de facto court investigators, thus creating conflicts of interest, breaching client confidentiality, and diminishing the prospect that attorneys will provide effective assistance of counsel."⁵⁷

Another issue called out is that in its minimal training, the Los Angeles Court gives court-appointed attorneys instruction that if they disagree with the "stated wishes" of the client, they should advocate for what they believe are the client's best interests.⁵⁸ While project

⁵⁵ Coleman, T. 2014.

⁵⁶ Ibid, p. 25.

⁵⁷ Ibid, p. 27.

⁵⁸ Ibid, p. 63.

informants point out that experienced conservatorship attorneys understand the duty to represent the proposed conservatee as specified in the Probate Code, this report concludes that such instructions can result in attorneys acting as de-facto guardians *ad litem*, advocating for what they believe are the best interests of the client rather than advocating for what the client expressly wants.⁵⁹ That outcome does not appear to be consistent with the intention and purpose of Limited Conservatorship process.

In addition, Limited Conservatorships are sometimes granted when the Regional Center report has not even been filed. Even when they are filed, these reports lack criteria and guidelines to make standardized and valid assessments of client capacities.⁶⁰ Furthermore, ongoing biennial investigations by the court investigator, required by state law, do not appear to be occurring in Los Angeles.⁶¹ Informants to this project report this lapse is occurring in other counties as well.

The *Justice Denied* report finds, and informants to the current study concur, that education about the I/DD population as well as about the conservatorship process itself, are severely lacking. Courts and attorneys need better education about the population, including the requirement and importance of providing reasonable accommodations under the Americans with Disabilities Act, in order for disabled persons to be able to communicate their views and wishes in the process.⁶² Parents and other potential conservators who file petitions need training about the conservatorship process, the duties and responsibilities of conservators, including the responsibility to take the disabled person's wishes into account even when they are conserved. All parties need better information about supported decision-making and appropriate alternatives to conservatorship.⁶³ Finally, neither the Department of Developmental Services nor a client rights advocacy agency has a formalized role in monitoring the Limited Conservatorship process.⁶⁴

⁵⁹ Ibid, p. 27.

⁶⁰ Ibid, p. 28.

⁶¹ Ibid, p. 26.

⁶² Ibid, p. 58.

⁶³ The Dale Law Firm of Walnut Creek, California provides trainings of this nature for family members and other proposed conservators as a public service (www.achievingindependence.com). Bet Tzedek is an agency located in Los Angeles that provides free comprehensive legal services to low-income individuals, running a regular clinic that assists families who need a conservatorship (<http://www.bettzedek.org/services/guardianships-and-conservatorships/>). However, such services are neither mandated nor funded and appear to be unique in the state.

⁶⁴ Coleman, T. 2014. p. 29.

Although some of these findings may be unique to Los Angeles County, many appear to have validity in other counties. As far as we are aware there is no quantitative study of the outcomes of Limited Conservatorships across the state of California; however, differing county-to-county processes are a significant problem in the applicability of statewide legal standards and of equity across counties. Each county's courts have differing policies and administration, which are often vastly different from one to the next.⁶⁵ This issue of local differences has also been reported as problematic in the way that each county's Adult Protective Services and Public Guardian's offices interact with Limited Conservatorships, LPS Conservatorships and issues of protection. El Dorado County for example will intervene in a case where a conservator is abusing a disabled person under his or her care, going so far as to become the Limited Conservator in order to protect the conservatee from further abuse or neglect. Other counties will not involve themselves. The variability in policies of locally administered agencies, both the courts and those under the domain of county boards of supervisors, vastly complicate the real-world outcomes of Limited Conservatorships and interventions in situations of abuse and neglect involved with bad conservatorships,⁶⁶ and deserve further study and recommendations for improvement.

People with intellectual and developmental disabilities have rights under both state and federal law that protect them in a variety of ways. Among these are the Lanterman Developmental Disabilities Services Act (Appendix C) located in California Welfare and Institutions Code. Section 4502 ensures the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws of the State of California, with protection against exclusion from participation, denial or discrimination under any program or activity that receives public funds. Section 4502.1 ensures the rights of individuals with I/DD to make choices about their own lives and requires public and private agencies to provide opportunities to exercise decision-making skills in any aspect of day-to-day living, provided in understandable form. Furthermore, Limited Conservatorship statutes require that under a conservatorship, the conservator is responsible to secure services which "will assist the limited conservatee in the development of maximum self-reliance and independence,"⁶⁷ and reserves all rights not explicitly granted to a conservator for the disabled person. All of these laws are intentional in preserving the independence and

⁶⁵ This feedback came from a number of informants. See also: Drought, T. 2004. pp. 1, 5, 7.

⁶⁶ This feedback received from a number of informants but most prominently from officials with Alta California Regional Center, located in northern California, who interact with many different counties in complex cases where a client has been abused or neglected. Staff, Alta California Regional Center, personal communication, 4/2/14.

⁶⁷ California Probate Code Section 2351.5. Retrieved on 7/13/14 from <http://www.saclaw.org/pages/conservatorship.aspx>. See Appendix B.

choices of people with I/DD, and providing respect and protection for their decisions. How these laws are administered in practice, however, has a significant impact on the ability of a disabled person to exercise decisions in his or her day-to-day life.

MEDICAL ISSUES

“Improving practices becomes an imperative for survival.”

–Theresa Drought, PhD, RN, Bioethicist

The role of conservatorship is seen differently depending on the vantage point of the observer. Conservatorship attorneys express that it is an appropriate tool depending on unique circumstances and individual and family needs; neither good nor bad but sometimes necessary. They emphasize the importance of conservatorship in protecting vulnerable people from harm, exploitation and abuse. Regional Center informants who see many complex situations report that in some cases family members have been the ones abusing disabled adults, and have used their status as conservator to obstruct investigation and intervention by Adult Protective Services. On the other hand, a father whose son is conserved uses the authority of conservatorship to help stand on his son’s side and empower his wishes when service providers and social workers try to “browbeat” or coerce his son to do things that are not in his interest.

Data from DDS show that most adults with I/DD in California are *not* under a Limited Conservatorship: approximately 71% are not conserved; 18% have a relative as a conservator; 8% have someone else as conservator; and less than 2% have a Public Guardian, DDS, a Regional Center Director or are a ward of the court. This may be attributable to a number of factors, including the growing understanding of the importance of self-determination, the capacity of people with I/DD to make their own decisions and the role of appropriate supports in assisting them to do so. Conservatorship is also relatively expensive; depending on a number of factors, it can cost upwards of \$5,000 to initiate and complete a conservatorship.⁶⁸ The cost and complexity of the process require some consideration of how important it may be for a formal conservatorship to be initiated, rather than relying on less formal methods of decision-making and support.

However, there are drivers that tend to increase the use of conservatorship that are not uniquely tailored to the needs and capabilities of the person and careful consideration of costs versus benefits. One of these situations is at the point when a youth with I/DD turns 18.

⁶⁸ Dale, Stephen. 2008. Limited Conservatorship Workshop.

Although special education laws entitle him or her to remain in school, developing skills and abilities up until age 22, informants report that schools frequently tell parents that they “must” get a conservatorship for their child at age 18 in order for them to continue their education. This statement is incorrect: conservatorship is not required – disabled students age 18 and over may sign a delegation of educational authority to allow their parents a continued role in educational decision-making. The other and most significant driver toward conservatorship is the complexity and demands of medical decision-making.

Medical Decision-Making Drives Conservatorship

Ironically, as the civil rights of persons with disabilities have advanced, institutionalization has been de-emphasized, and individual choice, independence and preferences have become better understood and accepted, a major federal policy initiative intended to offer privacy and protections has had the unintended consequence of increasing the need for conservatorship. The Health Insurance Portability and Accountability Act (HIPAA) was established in 1996 with the purpose of improving portability and continuity of health insurance coverage using national standards for electronic data interchange. It also mandates strict standards for ensuring privacy, confidentiality and security of healthcare information.⁶⁹

HIPAA has dramatically increased the need for conservatorships as hospitals, providers, schools and all other agencies with responsibility for its requirements must demand proper and formal authorization for sharing healthcare information. While there are other protections in state law that also deal with privacy,⁷⁰ one attorney has called the comprehensive impact of HIPAA “a nice idea gone bad,” asserting that many families are driven to seek conservatorships because of HIPAA compliance purposes *alone*, rather than because of any other guidance the disabled person needs in his or her life. This informant estimates that HIPAA requirements are responsible for upwards of 50% of the conservatorships sought in the 25 jurisdictions in which he works.⁷¹

The most direct solution for HIPAA-compliant information-sharing is a HIPAA release of information authorization; however, for people with I/DD in particular, the matter is more complex. To give a release of information the disabled person must be deemed competent,

⁶⁹ Dale, Stephen. *Privacy Issues for Persons with Developmental Disabilities* (powerpoint presentation). Conveyed by personal communication on 11/15/13. This presentation does not appear to be online.

⁷⁰ These include the California Constitution, Article 1, Section 1; the California Information Practices Act, Civil Code Section 1798 et seq.; and the Lanterman Developmental Disabilities Services Act, Welfare and Institution Code Section 4514.

⁷¹ Dale, Stephen. Personal communication on 11/25/13.

and this becomes a minefield for families as every agency staff needing a release questions the competency of the disabled person to sign it, often based on whether the person has what is perceived to be “normal” appearance. Competency is not a matter of appearance, nor is it easily discerned by front-desk staff responsible for securing releases. Therefore, in order to navigate daily life, the disabled person and family must make some formalized arrangement for healthcare information-sharing and when necessary, substituted decision-making. Securing a conservatorship so that a designated person is fully and easily authorized to give and receive healthcare information and make decisions is one solution to this dilemma. But there are alternatives.

Alternatives to Conservatorship for Healthcare Decisions

There are several alternatives to conservatorship for healthcare decision-making, including the use of an advance healthcare directive, petitioning the court for medical decision-making authority under the Probate Code, and utilizing the delegated authority of a Regional Center Director to the Regional Center Medical Director to authorize medical treatment.

Advance healthcare directives can be used when the person has capacity but needs help communicating or support in making decisions. (“Having capacity” means the person is competent to give or refuse informed consent for medical treatment – can respond knowingly and intelligently to queries about the proposed treatment, can participate in the treatment process through rational thinking, and can understand the fundamentals of medical treatment including understanding the nature and seriousness of the illness and recommended treatment, the probable degree and benefits of treatment, the consequences of lack of treatment and the nature, risks and benefits of alternatives.⁷²) The directive allows the disabled person to appoint someone on their own behalf and, in concert with a HIPAA Release, can address healthcare decision-making.

However, there are considerations about using advance healthcare directives for this purpose:

- The person must have capacity to engage in discussion about medical treatment, decisions and their advance healthcare directive. This is usually determined by the primary care physician. It is important to staple the capacity determination to the advance healthcare directive so that they always go together.

⁷²California Probate Code Section 1828.5. Retrieved on 7/13/14 from <http://www.saclaw.org/pages/conservatorship.aspx>.

- An advance healthcare directive is **revoked** the moment the disabled person disagrees with it. This can be an issue when anxiety about a medical treatment arises; for example, if the disabled person fears going to the dentist. If treatment is authorized by the appointee and the person balks at a procedure, the advance directive is revoked and has no force. This can present challenges in real-life situations.

When a disabled person does not have capacity to consent to a specific medical treatment, another alternative is the use of the court process under Probate Code 3200 *et seq.*⁷³ This provision allows someone to petition the court to determine whether a patient lacks the capacity to make a decision about a specified treatment, and if so, designates someone to make the decision on the patient's behalf. It can also be used to authorize treatment or non-treatment, including approving or disapproving diagnostic tests, surgical procedures and medications, selecting or discharging healthcare providers, and making a decision to provide, withhold or withdraw artificial nutrition and hydration and other forms of healthcare, including cardiopulmonary resuscitation.⁷⁴ This process is used by hospitals when a person requiring treatment cannot make a medical decision for themselves. It is also significant because a petition can seek a court determination that the individual *has* capacity to make decisions in his or her own behalf, which would obviate the need for a substitute decision-maker.

But in a number of large California counties, Probate Code 3200 is not routinely used, and some counties will not accept a 3200 petition. In lieu of this process, Santa Clara, Los Angeles, San Diego and other counties utilize a policy based on the American Bar Association 2003 publication *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly*. This report finds that solitary patients may be subject to overtreatment, undertreatment, or treatment that does not reflect their values or address their well-being.⁷⁵ Policies based on this publication allow for a subcommittee of the bioethics committee either to make a decision and provide consent, or to provide oversight of the medical team and

⁷³ California Probate Code 3200(b). Retrieved on 9/2/14 from <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=prob&group=03001-04000&file=3200-3212>.

⁷⁴ California Association of Mental Health Patients' Rights Advocates. *Patients' Rights Advocacy Manual, Chapter 6 – Informed Consent*. Retrieved on 9/2/14 from <http://www.camhpra.org/patients-rights-advocacy/chapter-6.html>.

⁷⁵ Karp, N. and Wood, E. *Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People*. ABA Publishing. Human Rights. Vol. 31 No. 2. Retrieved on 9/2/14 from http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol31_2004/spring2004/hr_spring04_incapacitated.html.

issue a review. The report quotes one hospital bioethicist as saying, "The single greatest category of problems we encounter are those that address the care of decisionally incapable patients... who have no living relative or friend who can be involved in the decision-making process. These are the most vulnerable patients because no one cares deeply if they live or die."⁷⁶ The Bar Association report advances workable solutions to preserve the rights and improve the outcomes for solitary patients. Policies based on *Incapacitated and Alone* are intended to provide a mechanism to address healthcare decisions for those without capacity or an advance healthcare directive or a substituted decision-maker in place at the end of life.⁷⁷

Another healthcare decision-making alternative is the authority of the Regional Center director utilized along with the resources of the IPP process. Under Welfare and Institutions Code 4655, the director of a Regional Center or his designee (usually the Medical Director) may give consent to medical, dental and surgical treatment of a client if there is not a "legally authorized" person or if that person does not respond within a reasonable timeframe to give consent.⁷⁸ If the disabled person is not conserved, such consent may be given only if s/he is incapable of giving consent. This authority can be used in cases where the person lacks capacity. Regional Center processes differ, but in some cases, specific health services can be specified in the IPP process and the Regional Center Medical Director would have the authority to authorize them.⁷⁹ Considerations include:

- The IPP process works better with specifics. Instead of saying, "Ms. Smith shall be healthy," it should provide details about the health care Ms. Smith requires to ensure the goal is met.
- While in some cases this may be a viable option, each Regional Center Medical Director has responsibility for thousands of clients and is unlikely to know each in person. In non-emergency situations, there may be a significant lapse in time before authorization can be secured. So, for cases where the person has chronic, fragile or rapidly evolving conditions, this process may not be best.

⁷⁶ Ibid.

⁷⁷ See Santa Clara County Medical Association *Recommendation for Establishing Policy on Health Care Decisions for Incapacitated Patients Without Surrogates*, February 2001. <http://www.sccma-mcms.org/Portals/19/assets/docs/No%20Surrogate%20Final.pdf>.

⁷⁸ California Welfare and Institutions Code 4655. Retrieved on 7/5/14 from <http://law.onecle.com/california/welfare/4655.html>.

⁷⁹ At one Regional Center, medical, dental or surgical services require separate authorization for each instance of treatment on an as-needed basis. Staff, Alta California Regional Center, personal communication, 8/22/14.

Explaining the alternatives to conservatorship for healthcare decision-making is not, by itself, a full solution. A conservatorship attorney who works with low-income families reports that tension often exists between parents and Regional Centers; families see conservatorship as a means of empowerment when Regional Centers are not responsive and do not give them a “say” in the type of services they receive. For these families, conservatorship can be seen as a strategy to navigate complex systems and advocate for services their loved one needs. This can be especially important for undocumented families. One measure intended to address this concern is SB 468 (Emmerson), passed in 2013. This bill requires DDS to apply for federal funding by December 31, 2014, in order to implement a state Self-Determination Program. The program would provide consumers and their families with an individual budget designed to increase flexibility and choice and provide greater control over decisions, resources, services and supports for Regional Center clients. If federal funding is approved, the program would be phased in over three years, eventually becoming available system-wide to all eligible Regional Center consumers who wish to participate.

End-of-Life Planning and Palliative Care

End-of-life planning is an ongoing series of choices, guided by values and life experiences about desired treatments, locations and experience of the quality of life at the end of life. The process of advance care planning educates patients about the expected course of their disease and solicits individual preferences about care, including potential interventions they may receive such as cardiopulmonary resuscitation, mechanical ventilation or artificial nutrition.⁸⁰ A patient may authorize some interventions and preclude others – advance care planning is completely tailored to individual preferences and desires.⁸¹ It may include discussion of the patient’s spiritual values, people to be included in the process, and the place as well as circumstances under which the person wishes to die.⁸² It typically designates a substituted decision-maker to make medical decisions for the patient when s/he is no longer able to do so. The patient’s choices are formalized through an advance healthcare directive (also known as a Living Will, Medical Power of Attorney or Power of Attorney for Healthcare). A Physician Order for Life Sustaining Treatment (POLST) is a more specific document that translates the patient’s choices into a set of medical orders written by a

⁸⁰ Center to Advance Palliative Care. 2012. *Palliative Care: What You Should Know*. Retrieved on 6/18/14 from www.getpalliativecare.org.

⁸¹ A POLST allows a person to say both what they do want as well as what they do not want, whereas a Do Not Resuscitate (DNR) order specifies only what a person does not want.

⁸² Center to Advance Palliative Care. 2012.

physician.⁸³ By means of an advance directive or POLST, a patient can prohibit aggressive resuscitation attempts in circumstances where s/he is nearing natural death.

Palliative care addresses serious illness, including terminal illness, and is an option that people may choose when making end-of-life decisions. While emergency healthcare responses focus first on sustaining life regardless of the burden of the treatment, palliative care is specialized medical care for people with serious illness. It provides patients with expert symptom management for relief of pain, fatigue, nausea, loss of appetite, constipation, shortness of breath, difficulty sleeping, pain and other symptoms. It supports family members and caregivers as well as the patient, and addresses the stress associated with serious illness. Palliative care provides extra time for communication and assistance in navigating the healthcare system, and helps people in practical ways to carry on with daily life, get through medical treatments, better understand their condition and make proactive decisions about their care. Palliative care is provided by a team including physicians, nurses, social workers, pharmacists, nutritionists, massage therapists and other professionals in a variety of settings including homes, hospitals, outpatient clinics, hospices and long-term care facilities. It is appropriate for a variety of conditions including cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's disease, HIV/AIDS, amyotrophic lateral sclerosis (ALS) and others, and can be provided at any stage of illness along with curative treatments.⁸⁴

Advance care planning involves understanding the risks and burdens of treatment in order to make meaningful choices. Because people with I/DD often experience difficulties in comprehending new or complex information or learning new skills, advance care planning for people with I/DD requires an emphasis on education, communication and skills development about health care, palliative care and end-of-life decision-making. There are a number of barriers to quality health care and planning for people with I/DD,⁸⁵ including:

- Negative health impacts of suboptimal nutrition, limited exercise and underutilization of health screening;
- Communication barriers that lead to more advanced presentation of illness before discovery;
- Lack of clarity of goals and poor definition of authorized decision-makers who can act on the patient's behalf;

⁸³ For further details about the differences between advance directives and POLST, the specific purpose and utility of each and how they work together, see

<http://med.fsu.edu/userFiles/file/POLST%20article%20by%20Dr.%20Dan%20Doty.pdf>.

⁸⁴ Center to Advance Palliative Care. 2012.

⁸⁵ Ellison, N. and Rosielle, D. November 2007. #192.

- Impact of denying people with I/DD opportunities for appropriate bereavement, knowledge of death of caregivers and loved ones and exclusion from rituals of death and dying;
- Lack of understanding of illness or misinterpretation of treatments “as punishment for wrong-doing;”⁸⁶
- Compromised symptom assessment and provider misunderstanding of somatic presentation of symptoms.

Providing effective palliative and supportive care for people with I/DD includes working with caregivers to maximize time in familiar surroundings, communicating in ways that are understandable to the patient, and symptom management that includes a focus on patterns of distress. It should also include thorough physical examinations, prudent use of diagnostic testing, and use of comfort medications. “Trial and error with constant monitoring of adverse medication effects” is often seen as necessary.⁸⁷

Clearly defining the risks and benefits of treatment so that the disabled person can make choices is essential to the process of care. Important considerations include whether treatments will be understood, whether the patient can comply with therapy, undue pain that may result from treatment, impacts to quality of life and usual routine and whether remission can be sustained long enough to justify the duration and side effects of therapy.⁸⁸ Clear and ongoing communication is necessary so that the disabled person understands these issues and can express wishes and desires about treatment.

Bioethicists have defined a standard “stepwise” approach to making crucial healthcare decisions when the patient lacks capacity, beginning with reliance on an advance directive. Optimally, the patient has defined choices about end-of-life care that will guide decisions. In the absence of an advance directive, the concept of substituted decision-making comes into play – a chosen surrogate speaks for what the patient would have wanted. Finally, if neither of these is available, the standard that is relied upon is the “best interests” of the person.⁸⁹ Informants to this project who are involved in end-of-life decisions emphasized that it is an ongoing process: It is “not a recipe and not a cookbook,” but rather a fluid and rapidly

⁸⁶ Ibid, p. 1.

⁸⁷ Ibid, p. 2.

⁸⁸ Ellison, N. and Rosielle, D. November 2007; #193.

⁸⁹ Torke, A, Alexander, G.C. and Lantos, J. *Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making*. Journal of General Interanal Medicine. September 2008; 23(9); 1514 – 1517. Retrieved on 6/28/14 from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518005/>.

evolving series of events and decisions that can address various contingencies. It is a plan of treatment rather than a discrete event.⁹⁰

Bioethicists also note that acute care settings are different than community settings, having their own processes, culture, regulatory framework and rapid timeframes in which decisions must be made. Doctors need training to talk to people about the end of life. In general, people greatly underestimate the complexities of the process and the reality of moving from the hypothetical to the real. "What cognitive capacity you have is the first thing hit when you are seriously ill; the second thing hit is emotional capacity." This occurs in a context where decisions must be made very quickly. "When capacity is compromised and lost, complicated systems of supported decision-making will break-down because of the immediacy of concerns." While a bio-ethics committee can be seen as a meaningful process to provide ethical guidance and decisions for those without capacity, an advance directive or a substituted decision-maker, one informant stated that "Not all bio-ethics committees are created equal," and there is little research into what makes a good bio-ethics process. People may or may not be well-served when a bio-ethics committee makes end-of-life decisions on their behalf. Knowledge, preparation and planning are essential to prepare for the eventuality of the end of life.

Meaningful end-of-life decision making, then, depends first on patient understanding and formal expression of choices, and then on effective substituted decision-making that can respond to unique developing circumstances. Too often for people with I/DD, these steps break down.

Breakdowns in the Medical Decision-Making Process

Because the end of life involves an ongoing series of events and decisions, substituted decision-making is typically an important factor for all populations, and the unique needs and complex barriers to good health care for people with I/DD amplify this issue. One critical matter for persons with I/DD involve the weakness of substituted judgment as well as shared decision-making in general.

Substituted judgment occurs when a delegated authority is authorized to make decisions on the principal's behalf, while *supported decision-making* elicits the wishes of the principal and provides support so that s/he can understand and make choices. *Shared decision-making* is

⁹⁰ Drought, T. 2004. *Medical Decision Making for Publicly Conserved Individuals: Policy Recommendations*. Retrieved on 6/7/14 from <http://www.scu.edu/ethics/practicing/focusareas/medical/conserved-patient/policy.html>.

a practice similar to supported decision-making that shares many of its attributes, used in healthcare to promote patient self-determination. It involves an interactive process in which both the physician and patient participate in decisions about treatment. The ideal process for shared decision-making was articulated by the President's Commission for the Study of Ethical Problems in Health Care and Biomedical and Behavioral research in 1982:

*"The physician brings his or her expertise on matters of diagnosis, prognosis, treatment and therapeutic alternatives, likelihood of success, and what to expect. The patient brings his or her expertise of living in the body being treated, as well as his or her values, spirituality, past experience, future goals, and personal orientation toward risk and life. The two, in negotiation, arrive at a mutually acceptable plan for care."*⁹¹

First, the physician role in advising on these issues depends very much on his or her experience with the person and understanding of issues of I/DD. However, physicians have "little insight into the patient's conception of what constitutes quality of life,"⁹² and according to both the literature and project informants, this is particularly true for people with I/DD.⁹³ Research also shows that people's wishes with regard to life-saving treatment change over time. This indicates the need for continuing planning and dialogue – specifying wishes in an advance directive should not be a one-time event, but an ongoing process. In addition, surrogate decisions have only been found to be an exact match for what the person would want for themselves 68% of the time; despite this, it is important to a majority of people that family members and physicians have input into their care.⁹⁴ This is because studies have shown that the patient is less concerned that the surrogate represents his or her exact wishes than that s/he be allowed to decide what is right in the moment. This relies on "trust and the symbolism of the relationship – that the surrogate *will care* what happens to the person and so will make the best decision possible."⁹⁵

This inference that a surrogate/substituted decision-maker will care is central. It is a standard that is hard to quantify as a matter of rights or procedures. While a conservator who is not acting in the best interests of a conservatee can and should be reported to the Probate court, real-world examples of poor end-of-life experiences for persons with I/DD occur. The situations encountered by the Coalition for Compassionate Care of California that

⁹¹ Ibid, p. 10.

⁹² Ibid, p. 10.

⁹³ See King, A., Janicki, M. et al. 2005. *End-of-life Care for People with Developmental Disabilities: Philosophy and Recommendations*. University at Albany Center for Excellence in Aging Services. Retrieved on 6/28/14 from <http://www.albany.edu/aging/lastpassages/lp-philosophy.htm>.

⁹⁴ Torke, A, Alexander, G.C. and Lantos, J. P. September 2008. P. 1515.

⁹⁵ Drought, T. 2004. p. 11.

precipitated this inquiry were validated by informants – there are instances where disabled people are “treated to death” against their wishes, are frightened or in pain or are cut off from people important to them at the end of their lives. An RN informant has seen these issues occur “very frequently.” One Regional Center official said, “We do not see a lot of cases like this, but I believe that they happen and could tell you far ahead of time the people that it is likely to happen to.” A Medical Director of a Regional Center expressed concern that financial interests of the disabled person’s family sometimes influence end-of-life choices – that decisions to end life are driven in some instances because of a financial incentive of a will or trust, and conversely that the end of life is painfully prolonged, solely because a family depends on the disabled person’s public benefits check, including income earned by family members for providing In-Home Supportive Services to the disabled person. Reporting these issues to Adult Protective Services has not been an effective intervention because none constitutes financial abuse, per se. Three medical professionals involved with the population also report that providers often misunderstand quality of life among the I/DD population and sometimes devalue their lives, resulting in physician advice to withhold interventions that would be seen as appropriate treatment to offer a non-disabled person.

In addition to these serious concerns, there is an array of complex medical/legal issues that arise from end-of-life decisions where a clear Advance Directive and a caring substituted decision-maker are not in place. These problems are especially pressing for individuals who are publicly conserved. The Public Guardian (PG) is hampered in substituted decision-making first because s/he may have little or no information about the patient’s wishes, and second because “a caring relationship with the patient in the manner of a family or friend” is lacking.⁹⁶

Although DDS data shows that currently only a small number of people fall into this category – 871 people statewide are reported to have a PG serving as their conservator – the department acknowledges that this number may be underreported. In addition, the aging of family members who traditionally fulfill the role of supportive decision-maker or conservator means that as the I/DD population ages, their natural family supports are likely to diminish and more will become reliant on public conservatorship.

The complexity and increased risk for publicly conserved individuals merit particular attention to their well-being across the lifespan and especially at the end of life. The problems they face were outlined in a 2004 report *Medical Decision Making for Publicly Conserved Individuals: Policy Recommendations*⁹⁷ by Theresa Drought, PhD, RN, who is now

⁹⁶ Ibid, p. 11

⁹⁷ Ibid.

Director of Medical Bioethics at Kaiser Permanente, Woodland Hills. This report summarizes four key areas of breakdown in the medical decision making process between physicians and the PG:

- **Documentation requirements**, especially where there is no Advance Directive or where it is not available when needed. In addition, obtaining the extensive documentation required for a court hearings about end-of-life decisions is extremely challenging in fluid, ambiguous and rapidly evolving situations.
- **Timely communication** back and forth between the PG and medical providers.
- **Distrust and lack of understanding about respective roles**, especially in that the physician and the PG both feel decisions are made by the other party to shift or avoid liability.
- **Misperceptions and Disagreements** over legal requirements and county differences in the application of laws.

The details of this report provide a useful blueprint for policy improvement and deserve further consideration in understanding and improving the specific conditions of persons with I/DD who are publicly conserved. The report provides an outline for practice improvements to the decision-making process so that it will be more person-centered, work more effectively and achieve better outcomes for the person and the system. These improvements involve better communication, collaboration and increasing understanding of roles and the regulatory and practice conditions under which both physicians and Public Guardians operate (see Appendix D: *Policy Recommendations for Improved Medical Decision-Making for Publicly Conserved Individuals*).

A key challenge to making improvements to processes of medical decision-making for the publicly conserved is the fact that Public Guardians (as well as courts) are locally administered, and each county and jurisdiction interprets and implements laws and policies differently. Drought comments, "The extreme variation in practices noted across counties seems to exceed what the ambiguities in the law might suggest."⁹⁸ Another informant stated, "The interlocking gears of these systems are not necessarily a good fit and at times create friction that is unbearable for the people who are caught in it." The Legislature and DDS have an interest in making these gears work more smoothly and ensuring that local policy is implemented with enough consistency so that clients of Regional Centers are protected and afforded the benefits of the Lanterman Act, no matter in which county they reside.

⁹⁸ Ibid, p. 7.

Puente Clinic San Mateo

Lack of understanding of people with I/DD, systems that do not work together, shifting risk back and forth, and difficulties navigating the complexities of both the legal and healthcare systems are contributors to poor outcomes as people with disabilities age and transition to the end of life. However, there are opportunities to improve these underlying conditions and provide more effective supports for good health care across the lifespan. The Puente Clinic of San Mateo County offers one such model.⁹⁹

The Puente Clinic is a program of the Behavioral Health and Recovery Services department of the San Mateo County health system. The clinic brings together collaborative resources of multiple agencies to address the most vulnerable persons with I/DD: those with co-occurring developmental disability and behavioral health conditions. The incidence of mental illness in persons with a developmental disability is three to five times greater than the general population, with approximately 20-25% of those with mild to moderate I/DD and nearly 50% of those with severe or profound I/DD having a co-occurring mental illness.¹⁰⁰ The causes are not fully understood, but negative social conditions are thought to play a role in creating high levels of emotional distress, including segregation, stigma, bullying and abuse. The complexity of needs combined with lack of appropriate services and ineffective systemic coordination put these consumers at high risk for negative outcomes such as homelessness, incarceration and institutionalization. According to DDS, 60% of those institutionalized in state Developmental Centers have co-occurring I/DD and mental health disabilities.¹⁰¹

The Puente Clinic is a collaboration of San Mateo County Behavioral Health, the local Regional Center (Golden Gate Regional Center) and the Health Plan of San Mateo (HPSM). Clinic staff are not co-located but are provided by a partnership among these agencies. This structure allows the work of the clinic to be sustainable. The coordinated work with HPSM and the Regional Center is the core of the model, although the clinic also brings in Public Guardians, Adult Protective Services, older adult community resources and other local agencies involved in a consumer's care. Efficiently combining a variety of human and fiscal resources, including the funding from California's dual eligible demonstration, the Puente Clinic provides enhanced care coordination and specialized resources. The actual staff of the Puente Clinic consists of psychiatrists and a social worker. A nurse providing coordination

⁹⁹ An overview of the Puente Clinic may be found at their website, <http://smchealth.org/bhrs/providers/puente>.

¹⁰⁰ Disability Rights California. Pub #CM27.01, October 2013. *Stop Segregation of People who have both Mental Health and Developmental Disabilities*. p. 1. Retrieved on 10/24/14 from <http://www.disabilityrightsca.org/pubs/CM2701.pdf>.

¹⁰¹ Ibid, p. 2.

for primary care comes from HPSM; a forensic social worker housed within the Regional Center performs capacity determinations. The majority of clients served by the Puente Clinic are not conserved, though Limited Conservatorship is an option should the need arise.

The Puente Clinic handles treatment consent with a process wherein the director of the regional center is the designated medical care signatory. Treatment consent occurs with the client, but is also reviewed by the Regional Center Medical Director and the behavioral health Medical Director or designee. The turn-around time for this review is one week.

The clinic provides one-time consultation, case coordination among all treating staff to plan for challenging circumstances, and continuing care services such as comprehensive mental health treatment and medication management. Services are provided in both the clinic and the consumer's home and focus on persons entering the community after institutional placement or at risk for higher levels of care, psychiatric emergency responses and issues of complex diagnosis or polypharmacy. The Puente Clinic also provides specialty and dental services. It is able to organize an array of recovery-oriented and flexible strategies that can solve problems and successfully address forensic and other complex concerns with a person-centered approach. The following vignette featuring the Puente Clinic's work illustrates how this model of intensive care coordination can address complex circumstances and improve health care and quality of life for people with I/DD.

Vignette: Improved Health Care through Collaboration¹⁰²

In July 2012, the Puente Clinic learned of a 58-year-old female ("Maria") who had been admitted to Mills Peninsula Hospital for failure to thrive. Maria had been living with her mother and sister and, according to her sister, was happy and active, described as a "people person" and a "go-getter." However, after her mother died in July 2011, Maria had become very depressed, stopped eating and would only get out of bed to use the restroom. Her weight dropped from 210 lbs. to 128 lbs. Six months prior to coming to the attention of the Puente Clinic, she had been hospitalized and then transferred to Mills Peninsula Extended Care Facility, a skilled nursing facility (SNF). During the transfer, Maria told her sister that the paramedics had "tossed her around like a cat," which caused her to fear falling and refuse to get out of bed. Maria had also undergone dental surgery that extracted 20 teeth, one week prior to hospitalization. After admission to the skilled nursing facility she

¹⁰² Adapted from vignette provided by Dr. Chris Esguerra, who was then serving as Deputy Medical Director and Medical Chief of Adult Services for Behavioral Health and Recovery Services and oversaw the Puente Clinic. Personal communication, 10/3/13.

underwent placement of a percutaneous endoscopic gastrostomy (PEG) tube and declined to non-ambulatory status.

The family did not seek Regional Center services until after the death of Maria's mother; Maria was made eligible for Regional Center services in April 2012. The case was referred to the Puente Clinic by a care coordination nurse case manager for Health Plan of San Mateo (HPSM), who contacted the Golden Gate Regional Center case manager and suggested a community placement in an Intermediate Care Facility (ICF). There were complications with the placement because of difficulties in sharing information between the ICF and the SNF, but the nurse case manager successfully navigated the placement. She then secured permission for the HPSM physician to follow Maria at home because of her fear of going out into the community, and worked closely with the Regional Center to get support in home day programming for Maria. Finally, she encouraged a referral to The Puente Clinic to obtain mental health services.

The Puente Clinic psychiatrist met with Maria at her home for an assessment, spoke at length on the phone with the client's sister for collaborative information and determined that there was no previous psychiatric history. He adjusted Maria's medications and consulted with the clinic behaviorist to formulate a plan for gradual exposure to strengthen the client, with a goal of addressing Maria's anxiety about falling and helping her to move toward ambulation. He also recommended the involvement of the Center for Behavioral Education and Management, a behavioral crisis intervention team, to address the client's generalized fears and assist in transitioning the client to attend a day program. Psychotherapy with a Puente clinician was also recommended.

A Puente Clinic therapist conducted a psychotherapy assessment of Maria in her home. In consultation with staff from the home, the therapist learned that Maria appeared more depressed on cloudy days and that she had experienced the loss of a sibling in the fall season. Light therapy was considered but light therapy medical devices are not currently covered by the Medi-Cal program.¹⁰³ The client was unable to respond verbally, so talk therapy was not seen as beneficial. Instead, considering that the client's symptoms were significantly organized around somatic responses, the Puente team decided that Somatic Therapy might be helpful.

¹⁰³ An informant from Disability Rights California notes that a Regional Center could potentially pay for this type of equipment.

Somatic Therapy, also known as Body Psychology, combines traditional psychological practice with understanding the critical role of the body in the construction and interpretation of the human psyche. Premised on unity and holism, it eliminates the distinction between the mind and body and assists clients to recognize and explore how they use their body to enact self-regard, identity, emotions, and relational connectivity in their daily, lived experience. Somatic Therapy is especially useful in helping clients expand ranges of expression and it promotes integration of changes clients work toward in therapy.

The somatic therapist was successful in engaging Maria by responding empathetically to facial cues, playing games and prompting and encouraging her to respond verbally. They engaged in collaborative play designed to elicit and access language, using a book on friendship and reading the book together. She also used mindfulness, communication worksheets, drawing and singing to draw Maria out. Through these approaches, the therapist was able to elicit feelings from Maria regarding relationships, and Maria began to display confidence in engaging in relationship with the therapist. Her communication improved -- her enunciation became clearer, she was speaking more loudly and needed fewer prompts to speak.

During one of the therapist's visits a doctor arrived to examine Maria, giving the therapist the opportunity to witness Maria's intense fear and physical reaction to the doctor. The therapist provided calm and soothing support, staying with Maria during the doctor visit. She was able to convey to Maria that this was a different doctor than the one who had extracted her teeth, which calmed Maria immediately. This provided valuable information regarding the extent of the trauma Maria underwent with her previous medical procedures and helped to inform her treatment plan.

Since that time, Maria has made significant progress, attributable to the collaboration of the Puente Clinic, the Health Plan of San Mateo, the Regional Center and input and cooperation from Maria's family and staff at the ICF. In Maria's case, her health was significantly improved and a conservatorship was avoided, by means of advanced care coordination and specialized services.

Other Initiatives

Effective care coordination can improve health care and in some cases avoid unnecessary conservatorship and institutionalization by providing appropriate supports to meet the person's needs. There are also initiatives that focus specifically on end-of-life planning that offer opportunities to support more person-centered care for people with I/DD at the end of life.

Senate Bill 1004 (Hernandez), signed by California Gov. Jerry Brown in September 2014, requires Medi-Cal to establish standards and provide technical assistance to Medi-Cal managed care plans and ensure the delivery of palliative care services to Medi-Cal beneficiaries.

SB 1004 requires the California Department of Health Care Services (DHCS) to (1) establish guidance on the medical conditions and prognoses that make a beneficiary eligible for the palliative care services, and (2) establish standards and provide technical assistance for Medi-Cal managed care plans to ensure delivery of palliative care services.

Palliative care is defined as specialized medical care and emotional and spiritual support for people with serious advanced illnesses that provides relief of symptoms, pain, and stress of serious illness, along with improving of the quality of life for both the patient and family, and is appropriate care for any age and for any stage of serious illness, along with curative treatment.

DHCS may implement the provisions of this section by means of all plan letters or similar instructions, without the adoption of regulations. To the extent practicable, palliative care services delivered pursuant to this law are to be provided in a manner that is cost neutral.

Inspired by California's successful pediatric palliative care program established in 2006, SB 1004 is intended to better address the preferences of adult patients facing advanced illness. The children's palliative care waiver program evaluation shows that providing palliative care concurrent with curative care improves quality of life, reduces average hospital stays by half and results in average cost savings of \$1,677 per child per month, allowing patients to live longer with fewer hospitalizations.¹⁰⁴

¹⁰⁴ California Senate Committee on Health. Analysis SB 1004. 5/5/14. Retrieved on 8/2/14 from <http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml>.

SB 1004 requires the DHCS to seek consultation with stakeholders in developing the program. This provides the opportunity to assist in developing programmatic elements that would provide access and improve the process of end-of-life planning for disabled adults, including family and provider education and individual supports.

In addition, the *Thinking Ahead* workbook (see Appendix F) is an end-of-life planning tool developed especially for persons with I/DD under a grant from the California Department of Developmental Services. Created by the Coalition for Compassionate Care of California in collaboration with the Board Resource Center and three Regional Centers,¹⁰⁵ *Thinking Ahead* was informed by people with I/DD themselves, who participated in focus groups, spoke in videos and reviewed materials to ensure that the materials reflected their concerns. *Thinking Ahead* workbooks and accompanying videos are available in English, Spanish and Chinese.¹⁰⁶

Workbooks and DVDs have been distributed through Regional Centers, at conferences and online. DDS and CCCC have also conducted training and workshops based on the materials for community care providers, providing information about palliative and end-of-life care and advance care planning for people with I/DD. These trainings focus on developing the knowledge skills and resources necessary to feel comfortable and confident talking about end-of-life issues with a person with I/DD and also assist caregivers to support and advocate for the treatment preferences of the disabled person. Unfortunately, much of the community training about end-of-life care for people with I/DD has been curtailed due to budget constraints. This training should be restored and expanded in order to meet the critical and growing needs of the aging I/DD population.

Informants value accessible materials like *Thinking Ahead*, but also emphasized that materials alone are only a part of the process. End-of-life planning requires a sophisticated approach and an ongoing conversation. A Regional Center Medical Director notes that without this depth, caregivers sometimes see it as an “assignment” to “sign people up” for an advance directive. This can lead to inappropriate prompting to make choices the caregiver sees as correct rather than a dynamic process of helping the disabled person to understand and express choices. This is not the purpose of *Thinking Ahead*. Ongoing training for the person, family and providers is needed to make advance planning reflect the disabled person’s wishes. In addition, end-of-life planning should be discussed and

¹⁰⁵ Alta California, Golden Gate and Eastern Los Angeles Regional Centers assisted in the development of *Thinking Ahead*.

¹⁰⁶ Found here <http://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>.

considered each year in the IPP process. Finally, strengthening the disabled person's autonomy, independence and his or her ability to make and express choices can be achieved through supported decision-making.

SUPPORTED DECISION-MAKING

"How do we make sure a person's rights are not taken away, like mine were?"

—Jenny Hatch, Self-Advocate

Jenny Hatch is a 30-year old woman with Down Syndrome who in 2012 lived with a family friend and worked at Village Thrift in Newport News, Virginia. She loved to organize jewelry and dress mannequins and was considered a dependable employee. Jenny rode her bicycle, used her cell phone, was on Facebook and emailed her friends. She had received a special education diploma from high school and in addition to her part-time job, had volunteered on a local political campaign. She was a member of the local Methodist church.¹⁰⁷

In March 2012 Jenny was hit by a car while riding her bike. Her back was injured and she was hospitalized. When she was released from the hospital she moved in with friends, who were also her employers at the thrift shop. She and her friends were happy with the arrangement, but Jenny needed additional services and supports to continue to live independently after her accident. In order to qualify for a Medicaid waiver that would provide the home- and community-based services she needed, Jenny had to move temporarily into a group home to meet waiver requirements. In July 2012 she qualified for the waiver and returned to live with her friends.¹⁰⁸

However, at this point Hatch's mother and stepfather intervened, filing for guardianship of Jenny (the equivalent of a conservatorship in California). They stated that they were worried about her safety; they were concerned that she was impulsive, gossiped on Facebook, incurred high telephone bills and flirted with boys.¹⁰⁹ Her parents felt that because Jenny's IQ is about 50 and she often expresses her desire to become President of the United States, she is incapable of making decisions. As a result, Jenny was placed in temporary guardianship in August 2012. She was removed from living with her friends and placed in a

¹⁰⁷ Fox, A. *Justice for Jenny*. Wavy.com, October 25, 2012. Retrieved on 8/3/14 from <http://jennyhatchproject.info/node/227>.

¹⁰⁸ Vargas, T. *Jenny Hatch: A timeline*. The Washington Post: Post Local, August 2, 2013. Retrieved on 8/3/14 from <http://apps.washingtonpost.com/g/page/local/jenny-hatch-a-timeline/250/>.

¹⁰⁹ Dvorak, P. *The disabled deserve the same rights as the rest of us*. Washington Post, October 24, 2013. Retrieved on 11/5/14 from http://www.washingtonpost.com/local/the-disabled-deserve-the-same-rights-as-the-rest-of-us/2013/10/24/79cbdea4-3cd9-11e3-a94f-b58017bfee6c_story.html.

group home, cutting her off all her previous social contacts. Anyone who wanted to see her was required to apply for permission. She was forced her to quit her job, her phone was taken away and her computer was confiscated. Her online passwords were changed so she did not have access to her accounts. For over a year, Jenny was required to remain in the group home against her will. She was unhappy and tried to run away four times.¹¹⁰

Jenny's friends, Jim Talbert and Kelly Morris, organized support for her. They turned their thrift shop into a "Justice for Jenny" campaign headquarters and spent over \$50,000 in legal fees to contest the case,¹¹¹ which became a bellwether event in civil rights for adults with I/DD. Americans with Disabilities Act expert Peter Blank testified that he could not recall seeing any contract as restrictive as this guardianship request: "In some sense, it's kind of a civil death, it's a complete removal of all decision making for the individual, as this is written."¹¹² He noted that the impact of the guardianship on Jenny could put her at risk for stagnation, regression and depression. Other experts who testified on Jenny's behalf emphasized that the case is about the larger issue of an individual's right to choose how to live and federal law requiring integration of people with disabilities into community settings, and that the Medicaid waiver services she now qualifies for provide a wide range of supports to assist her to live independently.

On August 2 2013, Newport News Circuit Court Judge David Pugh ruled that Jenny's preferences should be taken into account. He rejected her parents' guardianship request and instead designated Jenny's friends Morris and Talbert as her temporary guardians for a year, to assist her to develop full independence using supported decision-making and the assistance of home- and community-based services.¹¹³ As a result of this landmark legal battle, Jenny's lawyers, the Quality Trust for Individuals with Disabilities, created the Jenny Hatch Justice Project (JHJP).¹¹⁴ The Justice Project's purpose is to protect and promote the rights of disabled residents in Washington, D.C. and to promote research and best practices for supported decision-making and other less-restrictive alternatives to conservatorship in the United States and internationally.¹¹⁵ Their work includes resources that articulate and explain

¹¹⁰ Vargas, T. *Woman with Down syndrome prevails over parents in guardianship case*. Washington Post, August 2, 2014. Retrieved on 8/3/14 from http://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html.

¹¹¹ Ibid.

¹¹² Ibid.

¹¹³ Ibid.

¹¹⁴ The Jenny Hatch Justice Project's work can be found at <http://jennyhatchproject.info/home>.

¹¹⁵ Blanck, P. *The Jenny Hatch Justice Project: A Rights Movement at the Right Moment*. October 16, 2013. Retrieved on 8/3/14 from http://jennyhatchproject.info/pblanck_blog.

supported decision-making as well as exploring strategies, such as using special education transition services, to expand its use and effectiveness.

Overview of Supported Decision-Making

The experiences of Jenny Hatch exemplify a growing acknowledgement of the human rights of persons with I/DD and the shortcomings of substituted decision-making through legal conservatorship.¹¹⁶ Surrogate decision-making through conservatorship has been called “state sanctioned removal of personhood from an individual.”¹¹⁷ Internationally, the rights of persons with disabilities to independence and self-determination are becoming more widely recognized. While historically there has been a strong tradition of protection over autonomy for people with I/DD, supported decision-making is gaining prominence as a mechanism that is less restrictive and more appropriate than overbroad or undue conservatorship.

Making one’s own decisions is a basic right as well as a natural part of the human experience, guaranteed under the U.S. and state Constitutions as well as other laws. For non-disabled adults, those rights are not contingent upon the quality of decisions made.¹¹⁸ People are free to make mistakes, and learn from them (or not). Making decisions that may be unwise or involve risk does not typically imperil fundamental rights.

Supported decision-making (SDM) is a process of seeking assistance from chosen family members, friends or supporters to understand situations, consider options and use their help to make choices.¹¹⁹ Almost all adults utilize SDM at some time when they consult with trusted others to make important decisions. For disabled adults, SDM can be a new paradigm for decision-making; one that is increasingly seen as an alternative to conservatorship with its consequent loss of independence and civil rights. SDM empowers disabled individuals by ensuring that they are the ultimate decision-maker, but are provided with appropriate supports to make decisions.

¹¹⁶ The national literature refers to guardianship, the term used in many states. In California, guardianship refers specifically to custody of a minor, while adults are under “conservatorship.” We use the term conservatorship throughout this section to minimize this confusion.

¹¹⁷ Michael Black, quoted in Kohn et al, 2012. *Supported Decision-Making: A Viable Alternative to Guardianship?* p. 1120. Retrieved on 8/2/14 from [http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf).

¹¹⁸ Jenny Hatch Justice Project. 2014. *Supported Decision-Making: An Agenda for Action*. p. 7. Retrieved on 5/21/14 from <http://jennyhatchjusticeproject.org/node/264>.

¹¹⁹ Ibid, p. 1.

Supported decision-making models have four primary characteristics.¹²⁰ Most importantly, the disabled individual retains legal decision-making authority. The relationship is also entered into freely and terminated at will. The disabled individual actively participates in decision-making; and finally, decisions made with support are usually legally enforceable. In October 2013, the First Annual Symposium on Supported Decision-Making was held in Washington, D.C., and articulated several principles for implementing SDM:

- There should be recognition that everyone has an equal right to make their own decisions, regardless of diagnosis or functional challenges;
- There should be respect for the various opinions and experiences that have led parents and advocates to choose different options for decision-making; and
- There should be promotion of the use and development of practices that will provide people in need with support for individualized decision-making assistance with the minimum of restrictions.¹²¹

Advocates express concern about the appropriateness of systems that are dependent on overbroad conservatorship as a routine part of permanency planning for people with I/DD, asserting that laws are frequently misapplied. Although repeatedly proposed and sometimes implemented, “reforms have had remarkably little effect on judicial behavior,” and conservatorships are routinely granted.¹²² Research demonstrates that conservatorship can result in harm to the disabled person, hindering self-determination and community inclusion.¹²³ Overly broad conservatorship can leave people feeling isolated and lonely,¹²⁴ can cause depression, decrease motivation, create learned helplessness¹²⁵ and undermine the disabled person’s physical and psychological well-being by reducing their sense of control over their lives.¹²⁶

The legitimacy of conservatorship has also been questioned on the world stage. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD)¹²⁷ challenges

¹²⁰ Kohn et al, 2012. p. 1128.

¹²¹ Jenny Hatch Justice Project. 2014. p. 11.

¹²² Kohn et al, 2012. p. 1118.

¹²³ Jenny Hatch Justice Project. 2014. p. 3.

¹²⁴ Kohn et al, 2012. p. 1119.

¹²⁵ Martinis, J. *One Person, Many Choices: Using Special Education Transition Services to Increase Self-Direction and Decision-Making and Decrease Overbroad or Undue Guardianship.* p. 5. Retrieved on 3/17/14 from

http://jennyhatchproject.info/docs/publications/jhip_publications_draft_article_guardianship.pdf.

¹²⁶ Kohn et al, 2012. p. 1120.

¹²⁷ Although it is modeled on the Americans with Disabilities Act, as of this date the United States has not yet ratified the CRPD. 147 other nations have done so.

the system of substituted decision-making, stating that signatories to the agreement “reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law” and that parties “shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”¹²⁸ The CRPD goes on to state that safeguards and supports include respect for rights, will and preferences of the person and that any safeguards (such as conservatorship) should apply for the shortest time possible and be subject to regular review by a competent, independent and impartial authority or judicial body. The CRPD asserts that supported decision-making can be a key element in improving experiences and opportunities of persons with disabilities; some see the CRPD as *requiring* nations to adopt mechanisms for SDM.¹²⁹

As the population with I/DD ages, their parents may predecease them, destabilizing their decision-making systems. Individuals who have little experience making important life decisions because they have been giving few opportunities will be greatly impacted by the loss of their natural supports. This makes establishing new systems essential and development of SDM increasingly important. In contrast to conservatorship, SDM recognizes the personhood of people with I/DD and avoids stripping them of fundamental freedoms, while from a disability rights perspective, SDM is consistent with the social model of disability that avoids labeling and views supports as alternative methods of functioning.¹³⁰

It is important to note that the state of the art of SDM exists in the early stages. While several models of formalized SDM operate internationally,¹³¹ there is not much research. One comprehensive review by Kohn et al¹³² raises a number of important points: for example, while there is a growing body of literature about how SDM *should* work, there is far less information on how it does work. There is little information about the internal dynamics of SDM discussions, and almost no empirical evidence that SDM systems succeed in achieving their substantive goals. Also understudied are the effects on supporters’ psychological characteristics and outcomes – Kohn notes, “Another hypothesis . . . might be that continually participating in another person’s decision-making, without the ‘luxury’ of one party or the other simply making the decision, creates more stress.”¹³³ Most importantly, the review notes that SDM arrangements can create new opportunities for abuse, potentially

¹²⁸ United Nations. *Article 12, Convention on the Rights of Persons with Disabilities*. Retrieved on 8/2/14 from <http://www.un.org/disabilities/default.asp?id=272>. See Appendix G for the full text of Article 12.

¹²⁹ Kohn et al, 2012. p. 1113.

¹³⁰ Ibid, p. 1127.

¹³¹ Kohn et al document SDM systems in British Columbia, Sweden, Saskatchewan.

¹³² Found here: [http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf).

¹³³ Ibid, p. 1143.

allowing unaccountable third parties to improperly influence persons with I/DD, disempower them and undermine their rights. However, the outcomes of conservatorship are also not well-studied, so without more research it is impossible to conclude that conservatorship is a better intervention than SDM.

Supported decision-making can be informal, done without legal sanction or enforceability.¹³⁴ Since approximately 71% of Regional Center clients are not under conservatorship, it can be assumed that informal SDM is already part of many people's decision-making process. But SDM can also be a formal system: based on either private but legally significant agreements; or on public appointments.¹³⁵ Some propose that SDM could take the place of conservatorship. Alternatively, it could be integrated into the legal system as a less-restrictive option that is implemented prior to the time that a Limited Conservatorship is even considered, resorting to the more restrictive option only when SDM arrangements have not functioned successfully.

The evolution of SDM should include empirical evidence about how to ensure that decisions truly express and effectuate the wishes or preferences of the disabled person and whether SDM decisions are more beneficial to the person compared to decisions made using other approaches such as conservatorship.¹³⁶ Overall, Kohn et al conclude that SDM holds promise from a public health perspective that it can improve overall physical and psychological well-being of people with I/DD, as well as being a less-restrictive method of decision-making which has the potential to advance the interests and human rights of people with disabilities.¹³⁷

Utilizing Special Education to Advance Supported Decision-making

What is the impact of supported decision-making on healthcare decisions and end-of-life planning and care? Research shows that patient activation -- the confidence and skills patients have to become actively engaged in their own health care -- can lead to better health outcomes and care experiences. Patients who start at the lowest level of activation show the greatest improvements.¹³⁸ Healthcare decisions and outcomes, and ultimately end-of-life decision-making, depend to a large degree on the other end of the life spectrum;

¹³⁴ Ibid, p. 1121.

¹³⁵ Ibid, p. 1121.

¹³⁶ Ibid, p. 1138.

¹³⁷ Ibid, p. 1138.

¹³⁸ Hibbard, J. and Greene, J. 2013. *What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data on Costs*. Retrieved on 8/7/14 from <http://content.healthaffairs.org/content/32/2/207.abstract>.

teaching and empowering people with skills to make choices and decisions. And an important opportunity to increase decision-making skills for people with I/DD is in special education.

Special education is governed by the Individuals with Disabilities Education Act (IDEA), passed in 1975. The IDEA states that “disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society” and it ensures that “all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living.”¹³⁹ Prior to passage of the IDEA, as few as 20% of students with disabilities received any type of education.¹⁴⁰

The IDEA guarantees students with disabilities the right to education up until 22 years of age. Designed to be a results-oriented process that improves the academic and functional achievement of the student, it focuses attention on transition from school to the next phase of life, such as post-secondary education, vocational education, integrated and supported employment, continuing and adult education, adult services, independent living and community participation.¹⁴¹ Research shows that students with disabilities who are provided with meaningful transition services that are focused on self-determination and independent living skills are more likely to experience good outcomes, including employment, living independently, exercising effective choices, making decisions and problem-solving.¹⁴²

Similarly to the IPP process used by Regional Centers, the IDEA functions from individualized assessment and planning that addresses students’ needs. In special education this is called the Individualized Educational Planning (IEP) process. The Jenny Hatch Justice Project notes in a policy brief that there are a number of models that effectively utilize the IEP process and demonstrate positive outcomes for students with I/DD to develop good transitional skills and abilities that support decision-making. These include the Youth Transition Project, the Self-Determined Learning Model of Instruction and Project Renew. These models promote self-determination as a best practice and focus on improving students’ abilities to set goals, solve problems, make decisions and advocate for themselves, and give students the opportunity to

¹³⁹ United States Public Law 108-446. 2004. *Individuals with Disabilities Education Act*. Retrieved on 8/7/14 from <http://idea.ed.gov/download/statute.html>.

¹⁴⁰ Martinis, J. 2013. p. 12.

¹⁴¹ Ibid.

¹⁴² Ibid, p. 13.

practice these skills.¹⁴³ They are generally based in interagency coordination that clearly articulates roles, responsibilities, communication strategies and other collaborative actions that leverage systems like vocational rehabilitation, independent living centers, the Social Security Administration and state and local agencies that provide services to persons with I/DD to create a service package and relevant strategies that prepare and transition the student into adult life.

Effective transition through special education can have lasting impacts on lives and health of disabled individuals. One study showed that women with I/DD who were provided with education and training in self-determination were more likely to identify situations where they could be abused and less likely to be victimized.¹⁴⁴ Another found that adults with I/DD who exercised self-determination showed greater independence, were more skilled at solving problems and achieved better outcomes overall.¹⁴⁵

However, disability rights advocates who focus on special education note that these outcomes are frequently unrealized in California. One informant outlined transition services as sub-standard, a significant missed opportunity to strengthen and prepare students with disabilities for adult life. While “person-centered planning” is said to be in effect, the focus of special education is reported to be superficial, focused around ensuring student compliance in academics and behavior rather than on “preparing them for further education, employment and independent living” as the IDEA intends. Furthermore, compliance is reinforced with punitive measures such as seclusion and restraints. Informants report that relevant skills that are needed to address real life -- such as understanding sex, health care and medications, or basic strategies like not arguing when confronted by police -- are missing. Interagency collaboration may be a goal, but in real life support agencies do not typically get involved in IEP processes and students are not empowered to define their goals and receive assistance in securing the skills and training they need to achieve them. Furthermore, according to informants, there is tension between schools and Regional Centers, each of which tries to shift responsibility for paying for services for the transition-aged population to the other.

The resulting dysfunction is evidenced in student outcomes. In June 2012, the United States Department of Education Office of Special Education and Rehabilitative Services found that California is achieving “a very low level of compliance” with transition requirements. In a

¹⁴³ Ibid.

¹⁴⁴ Ibid, p. 14.

¹⁴⁵ Ibid.

letter to State Superintendent Tom Torlakson, the U.S. Education Department states that California's compliance with Indicator 13, which measures appropriate transition services, is only 45.9% (see Appendix H). The letter states that California needs intervention in implementing the requirements of Part B of IDEA regarding effective transitions for students with disabilities.

The federal requirement for California to improve transition services is an important opportunity to improve supported decision-making skills. The Ansell-Casey Lifeskills Assessment provides an outline of effective approaches for IEPs that support appropriate transitions to adult life. These focus on a full range of transition skills including career planning, communication, daily living, home life, housing and money management, self care, social relationships, work life and work and study skills.¹⁴⁶ Assessing for these skills means understanding the student's current level of knowledge to target learning, incorporating the family and other professionals in transition teams, using observation and work experience to identify the student's preferences, observing interactions at school, with the family, in the community and during leisure and recreational activities, building rapport with the student, using surveys, questionnaires and interviews to gather information.¹⁴⁷ These assessment strategies can be used to guide postsecondary and transitional goals and assist in developing meaningful IEPs that provide support for self-determination and independent living, and consequently, healthcare decision-making.

¹⁴⁶ Casey Family Programs. 2011. *Lifeskills*. Retrieved on 8/5/14 from <http://lifeskills.casey.org/>.

¹⁴⁷ Steinman, K. *Expectation vs. Perspective: A personal experience of completing transition from high school to community*. pp. 31-32. Retrieved on 8/2/14 from <http://encompass.eku.edu/cgi/viewcontent.cgi?article=1134&context=etd>.

Figure 3: Jim Talbert, Kelly Morris and Jenny Hatch



Photo: ELINOR CARUCCI

Woman with Down Syndrome Fights for Her Freedom – and Wins

Date: Friday, March 7, 2014

News Source: People Magazine News

Author: Cathy Free and Nicole Weisensee Egan

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Retrieved on 8/3/14 from http://jennyhatchproject.info/030714_people.

FINDINGS & RECOMMENDATIONS

“Change will not come if we wait for some other person, or if we wait for some other time.”

– Barack Obama

The following recommendations are based on our review of the literature, incorporation of best practices identified in cited works and the practical experience of key informants. They include recommendations in each of five critical areas, and they address both policy and funding that are important to improve the area of healthcare decision-making for people with I/DD.

RECOMMENDATIONS

Legal System

- 1) **California probate codes governing Limited Conservatorship (Probate Code §§ 1827.5, 1828.5, 1830, & 2351.5) should be amended** to require that any client of a Regional Center may be subject only to a Limited Conservatorship rather than a General Conservatorship. General conservatorships for Regional Center clients should be prohibited.
- 2) **These Limited Conservatorship statutes should also be amended** to include a meaningful requirement that alternatives to conservatorship were understood, explored and an explanation of the reasons why they were unsuccessful and conservatorship is needed, as part of the process of petitioning for a Limited Conservatorship.
- 3) **Training about the I/DD population and the process, duties and responsibilities of Limited Conservatorship** should be formally initiated for those seeking to petition for conservatorship as well as for attorneys who work on Limited Conservatorship. These trainings should include information about facilitating communication and providing reasonable accommodations under the Americans with Disabilities Act to allow disabled persons to have meaningful participation in the legal process.
- 4) **The Legislature, in consultation with DDS, Regional Centers and the state’s protection and advocacy agency, should undertake a series of special hearings** to consider critical issues that are primarily locally-administered but have a substantial impact on persons with

I/DD who may be subject to neglect or abuse. A statewide approach and legislation may be necessary regarding two critical issues:

- The role of the Public Guardian and Adult Protective Services in interventions for people with I/DD who may be subject to neglect or abuse; and also in issues of end-of-life decision-making;
- The role, processes and effectiveness of courts in investigating, intervening and changing troubled conservatorships.

5) A disability clients' rights and protection organization with legal experience should be funded through contract with DDS and authorized to provide oversight, monitoring, reporting and policy recommendations on the Limited Conservatorship process statewide.

California Department of Developmental Services

6) DDS should initiate a survey among Regional Center Medical Directors, soliciting their input concerning situations that occur in end-of-life care for the I/DD population. From these survey results they should formulate a plan of action to change policies and initiate action to prevent poor outcomes. Our inquiry indicates that there are important concerns in three major areas:

- A) Comfort of care is not fully and adequately considered as part of the decision-making process when the Regional Center director's designee is the medical decision-maker;
- B) Conversely, hospitals and providers are too quick to underestimate quality of life for persons with I/DD and to dismiss life-saving interventions when they may be appropriate;
- C) Finally, when surrogate decision-makers may have a financial interest in either prolonging or ending life and their decision-making appears to be influenced by these concerns rather than the best interests of the disabled person -- what are the steps to take in such a case and how effective are they?

7) DDS should initiate and implement a strategic plan for end-of-life planning for persons with I/DD using best practices in advance care planning and building on the Thinking Ahead accessible advance directive materials. This initiative should include tools and skills training for end-of-life planning. As part of this effort, *IPPs for adults should include age-appropriate discussion of and support for end-of-life planning every year, including*

participation (as desired by consumer) in culturally appropriate recognition of grief, death and dying, such as participation in funerals and memorial services.

8) DDS should reinstate and expand community education aimed at providers regarding medical issues and end-of-life care for the I/DD population; making a request to the Legislature for funding to support this activity specifically. This training should include special considerations for aging and medical care for people with I/DD as well as understanding baseline quality of life for people with I/DD from their own and their families' perspectives.

9) DDS should refine and improve its data collection on conservatorship, including specifically tracking three vulnerable populations:

- Those who have a Limited or General conservatorship as well as an LPS Conservatorship.
- Those served by a Public Guardian as their conservator.
- Those flagged by Regional Centers as having a conservator who has been reported to Adult Protective Services for suspected abuse or neglect.

With this information, we recommend the Department convene a process and make focused recommendations for state law and policies to address the needs of these vulnerable subsets of the population.

Medical Systems

10) The California Department of Health Care Services, in consultation with DDS and the Health Plan of San Mateo, should explore methods to leverage the Dual Eligible Demonstration and other system change initiatives in order to utilize and deploy care coordination strategies to increase autonomy, provide appropriate supports, improved health care and end-of-life planning through collaborative work such as that being done at the Puente Clinic of San Mateo.

11) The Department of Health Care Services, DDS and I/DD stakeholders and advocates should explore the feasibility of adding educational end-of-life planning services supportive of persons with I/DD, their families and caregivers under the SB 1004 stakeholder process that will provide guidance to Medi-Cal managed care plans on providing access to palliative care services for adults in the Medi-Cal program.

12) The California Medical Practice Act which provides for the licensure and regulation of physicians by the Medical Board of California, should add requirements for training in the unique medical, psychosocial and communication needs of persons with I/DD.

13) **California should launch and evaluate a pilot study** to support implementation of a collaborative model that includes officials of the Court, the Public Guardian, the Regional Center and bio-ethics professionals, to improve medical decision-making for publicly conserved individuals as recommended in the Drought report (<http://www.scu.edu/ethics/practicing/focusareas/medical/conserved-patient/policy.html>).

Educational System

14) **Schools should be required to provide students and families who are transitioning to adulthood a full explanation of educational decision-making options**, including the option to partially or totally delegate educational authority to a family member, as an alternative to conservatorship, for making educational decisions. They should be prohibited from telling parents they “must” have a conservatorship to continue child’s education after 18.

15) **The Legislature should exercise oversight in the improvement of special education Indicator 13.** The U.S. Department of Education finds that California needs intervention to provide effective transition services. While these improvements will be located in the educational system, their importance to issues of healthcare decision-making as well as avoiding undue and overbroad conservatorship are paramount. Ideally, legislative oversight will involve a variety of stakeholders and informants to participate in designing improvements and ensuring that supported decision-making is expanded and self-determination and independent living are achieved within special education transition services.

General

16) **Regional Center funding that has been cut should be restored** in order to ensure that services are adequate, caseloads are manageable, individualized assessments are appropriately conducted and public educational efforts are restored.

17) **Court funding should be restored** to eliminate chaos in operations and ensure that the requirements of the 2006 Omnibus reform legislation are fully implemented. Within these restorations, funds should be earmarked to support the proper implementation and oversight of Limited Conservatorships, based on compliance with legal requirements for initial, annual and biennial investigations by court investigators.

CONCLUDING COMMENTS

As a general observation, this investigation raised important issues that appear to be neglected in research. While our goal was to understand the impact of conservatorship on people's experience of aging and dying, we discovered a number of complex legal and practical debates exist that are not well-studied. Legal status and systems of protection fail to work together for the best interests of disabled persons throughout their lives, not just at the end of life. There are important considerations about expression of human sexuality that need careful thought, dialogue and deliberation, with the most important voices in the conversation being people with disabilities themselves. In addition, persons with co-occurring I/DD and mental health disabilities are particularly vulnerable and subject to poor outcomes as a result of systems that do not begin to address their needs. And while we intended to study how legal issues may result in disabled persons being "treated to death" against their will, we also discovered that among those with roles in end-of-life care, there is a conviction that disabled lives are devalued in medical settings and life-saving care when appropriate is sometimes denied. These findings are deeply concerning and indicate that a range of important issues impacting the lives of persons with I/DD are overlooked and deserve wider research and policy consideration.

Research does show that conservatorship in and of itself can result in adverse consequences, including depression, decreased motivation, learned helplessness and feelings of diminished self-determination and empowerment.¹⁴⁸ However, it is also difficult to second-guess individual situations which depend on unique circumstances – the level of the person's disability, the person's and family's experiences balancing independence versus protection from bad outcomes, and the extent to which effective resources and services are in place to enable and support decision-making. As a practical matter, families are often simply trying to come up with a workable system, especially for navigating healthcare decisions.

Though project informants had diverse perspectives about conservatorship, they agreed on a number of points. First, they reported that mainstream society operates from a lack of understanding, experience and acceptance of people with I/DD, often influenced by perceptions of "normalcy" of appearance or behavior. They also report that as a result, people with mild to moderate disabilities are widely underestimated in their capacities for independence and decision-making. In addition, people with moderate to severe disabilities are also underestimated in their ability to make choices, but may require more supports to

¹⁴⁸ Martinis, J. 2013.

make their preferences meaningful and effective. These supports span the range of options from good care coordination to intensive supported decision-making to Limited Conservatorship, depending on the situation. The optimal solution is the least restrictive intervention that also yields effective results.

Informants agree that systems serving older adults, especially medical systems, are not prepared with the appropriate knowledge, services and supports for people with I/DD. And while they see the causes of bad conservatorships differently, project informants also believe that when conservatorships are bad, the situation is difficult to address. In these cases, the disabled person is at grave risk and appropriate remedies, supports and alternatives are scarce. As mentioned, informants consistently highlighted the vulnerability of people with dual I/DD and mental health disabilities, and we believe the urgency conveyed about this topic merits further research and policy action.

Finally, from wherever in the system they stand, informants are concerned that persons with I/DD be afforded the opportunity to age well as well as to die with dignity and respect. We hope that this investigation will make a contribution toward achieving that aim.

ADVISORY COMMITTEE

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APPENDICES

- Appendix A: County of Los Angeles Department of Mental Health, Office of the Public Guardian: End-of-Life Request by Treating Physician
- Appendix B: California Probate Codes Governing Limited Conservatorship
- Appendix C: Consumer Rights from Lanterman Act
- Appendix D: Policy Recommendations for Improved Medical Decision-Making for Publicly Conserved Individuals
- Appendix E: *Thinking Ahead: My Way, My Choice, My Life at the End*, an Accessible Advance Directive Workbook
- Appendix F: Article 12 United Nations Convention on the Rights of Persons with Disabilities
- Appendix G: California Deficiency in Special Education Transition Services