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DEVELOPMENTAL DISABILITY AND GUARDIANSHIP/CONSERVATORSHIP

1 1. WHAT IS DEVELOPMENTAL DISABILITY

2 For the purposes of this discussion, Developmental Disability must appear before the individual reaches
3 age 22. See Idaho Statutes below. Since DD symptoms and diagnosis usually occur while the person is
4 young, the general research and information is heavily accenting children.

5 a. General definition: Developmental disability is a diverse group of chronic conditions that are due to
6 mental or physical impairments. Developmental disabilities cause individuals living with them many
7 difficulties in certain areas of life, especially in “language, mobility, learning, self-help, and independent
8 living”. Developmental disabilities can be detected early on, and do persist throughout an individual's
9 lifespan. Developmental disability that affects all areas of a child's development is sometimes referred to
10 as global developmental delay.

11 b. Most common developmental disabilities:

12 ● Fragile X syndrome (FXS) is thought to cause autism and intellectual disability, usually among
13 boys (about 1 in 5,000 in US). It is the most common known cause of inherited intellectual disability.
14 Specifically, it is caused by changes in the fragile X mental retardation 1 (FMR1) gene, which
15 usually makes a protein called fragile X mental retardation protein (FMRP), needed for normal brain
16 development. There is usually some degree of intellectual disability, ranging from mild to severe,
17 but much less in females. Signs are developmental delays, learning disabilities, and social and
18 behavior problems, including hand flapping. Average age of diagnosis in boys is 36 months, 42
19 months for girls, but symptoms are usually noticed by parents much earlier. FXS can be diagnosed
20 by DNA testing. There is no cure for FXS, but treatment services can teach skills and control some
21 issues.

22 ● Autism Spectrum Disorder (ASD) is a group of developmental disabilities that can cause
23 significant social, communication, and behavioral challenges. ASD people may communicate,
24 interact, behave, and learn in ways that are different from most people. The learning, thinking, and
25 problem-solving abilities of people with ASD can range from gifted to severely challenged. There
26 might be repetitive behavior and requirement of rigid schedules, and often trouble relating to others.
27 ASD includes autistic disorder, pervasive developmental disorder not otherwise specified (PDD-
28 NOS, and Asperger syndrome, all of which were previously diagnosed separately.

29 ● Down syndrome is a condition in which people are born with an extra copy of chromosome 21,
30 resulting in 47 chromosomes, and sometimes called trisomy 21 because there three number 21
31 chromosomes - about 95% of Down syndrome cases. Normally, a person is born with two copies
32 of chromosome 21. However, if they are born with Down syndrome, they have an extra copy of this
33 chromosome. This extra copy affects the development of the body and brain, causing physical and
34 mental challenges for the individual. Some degree of intellectual disability (varying widely, but most
35 mild to moderate and, with proper intervention, few severe), characteristic facial and body features
36 (eye slanting upward, small ears, small mouth, small nose with flattened nasal bridge, short neck,
37 small hands and feet, short stature, and low muscle tone), and often heart defects (about half),

1 vision (60%), hearing loss (75%) and other health problems. Tend to develop Alzheimer's earlier
2 and more often than general public (about 25% over age 35 have symptoms). Severity varies
3 widely. About 1 in 700 babies each year in US. Currently more than 400,000 in US.

4 ● Pervasive developmental disorders (PDD) are a group of developmental disabilities that can
5 cause significant social, communication and behavioral challenges.

6 ● Fetal alcohol spectrum disorders (FASD) are a group of conditions that can occur in a person
7 whose mother drank alcohol during pregnancy. FASD's are 100% preventable if a woman does not
8 drink alcohol during pregnancy. There are a whole range of effects and can range from mild to
9 severe. Can include abnormal facial features, small head size, shorter than average height, low
10 body weight, poor coordination, hyperactivity, difficulty in concentration, poor memory, learning
11 disabilities, poor reasoning, vision or hearing problems, and heart, kidney, or bone problems.

12 ● Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain
13 balance and posture. CP is the most common motor disability in childhood, an estimated 1 in 323
14 children in US. Symptoms vary greatly and can change over time, but CP itself does not get worse
15 over time.

16 ● Intellectual disability is defined as an IQ below 70 along with limitations in adaptive functioning
17 and onset before the age of 21 (in Idaho) years.

18 ● ADHD (Attention-Deficit/Hyperactivity Disorder) - may have trouble paying attention, controlling
19 impulsive behaviors (acting without thinking about results), or be over active. Cannot be cured, but
20 can be successfully managed and some symptoms may improve with age. Idaho is on the low end
21 of statistics about medication or behavioral therapy treatment percentages.

22 There a lot more, but relatively rare.

23 c. Causes

24 The causes of developmental disabilities are varied and remain unknown in a large proportion of cases.
25 Even in cases of known etiology, the line between "cause" and "effect" is not always clear leading to
26 challenges in efforts to categorize causes. Genetic factors have long been implicated in the causation of
27 developmental disabilities. There is also a large environmental component to these conditions, and the
28 relative contributions of nature versus nurture have been debated for decades. Current theories on
29 causation focus on genetic factors, and over 1,000 known genetic conditions include developmental
30 disabilities as a symptom.

31 Developmental disabilities affect between 1 and 2% of the population in most western countries, although
32 many government sources acknowledge that statistics are flawed in this area. The worldwide proportion
33 of people with developmental disabilities is believed to be approximately 1.4%. It is twice as common in
34 males as in females, and some researchers have found that the prevalence of mild developmental
35 disabilities is likely to be higher in areas of poverty and deprivation, and among people of certain
36 ethnicities. Most websites I visit state that about 1 in 6 children have a developmental disability.

37 d. Diagnosis and quantification

38 Developmental disabilities can be initially suspected when a child does not reach expected child
39 development stages. Subsequently, a differential diagnosis may be used to diagnose an underlying
40 disease, which may include a physical examination and genetic tests. The degree of disability can be
41 quantified by assigning a developmental age to a person, which is age of the group into which test scores
42 place the person. This, in turn, can be used to calculate a developmental quotient (DQ): $DQ =$
43 $\frac{\text{Developmental age}}{\text{Chronological age}} * 100$.

44 e. Associated issues

1 i. Physical health issues

2 There are many physical health factors associated with developmental disabilities. For some
3 specific syndromes and diagnoses, these are inherent, such as poor heart function in people with
4 Down syndrome. People with severe communication difficulties find it difficult to articulate their
5 health needs, and without adequate support and education might not recognize ill health. Epilepsy,
6 sensory problems (such as poor vision and hearing), obesity and poor dental health are
7 over-represented in this population. Life expectancy among people with developmental disabilities
8 as a group is estimated at 20 years below average, although this is improving with advancements
9 in adaptive and medical technologies, and as people are leading healthier, more fulfilling lives, and
10 some conditions (such as Freeman-Sheldon syndrome) do not impact life expectancy.

11 ii. Mental health issues (dual diagnoses)

12 Mental health issues, and psychiatric illnesses, are more likely to occur in people with
13 developmental disabilities than in the general population. A number of factors are attributed to the
14 high incidence rate of dual diagnoses:

- 15 ● The high likelihood of encountering traumatic events throughout their lifetime (such as
16 abandonment by loved ones, abuse, bullying and harassment)
- 17 ● The social and developmental restrictions placed upon people with developmental
18 disabilities (such as lack of education, poverty, limited employment opportunities, limited
19 opportunities for fulfilling relationships, boredom)
- 20 ● Biological factors (such as brain injury, epilepsy, illicit and prescribed drug and alcohol
21 misuse)
- 22 ● Developmental factors (such as lack of understanding of social norms and appropriate
23 behavior, inability of those around to allow/understand expressions of grief and other
24 human emotions)

25 iii. External monitoring factor: All people with developmental disabilities that are in a federal or state
26 funded residence require the residence to have some form of behavioral monitoring for each
27 person with developmental disability at the residence. With this information psychological
28 diagnoses are more easily given than with the general population that has less consistent
29 monitoring.

30 iv. Access to health care providers: In the United States, all people with developmental disabilities
31 that are in a federal- or state-funded residence require the residence to have annual visits to
32 various health care providers. With consistent visits to health care providers more people with
33 developmental disabilities are likely to receive appropriate treatment than the general population
34 that is not required to visit various health care providers.

35 These problems are exacerbated by difficulties in diagnosis of mental health issues, and in appropriate
36 treatment and medication, as for physical health issues.

37 f. Abuse and vulnerability

38 Abuse is a significant issue for people with developmental disabilities, and as a group they are regarded
39 as vulnerable people in most jurisdictions. Common types of abuse include:

- 40 ● Physical abuse (withholding food, hitting, punching, pushing, etc.)
- 41 ● Neglect (withholding help when required, e.g., assistance with personal hygiene)

- 1 ● Sexual abuse is associated with psychological disturbance. Sequeira, Howlin & Hollins found that
2 sexual abuse was associated with increased rates of mental illness and behavioral problems,
3 including symptoms of post-traumatic stress. Psychological reactions to abuse were similar to those
4 observed in the general population, but with the addition of stereotypical behavior. The more
5 serious the abuse, the more severe the symptoms that were reported. There is a special place in
6 Hell for people who sexually abuse the vulnerable. See, for more information, the following site:
7 [16]<http://bjp.rcpsych.org/content/bjprcpsych/183/5/451.full.pdf>
8 ● Psychological or emotional abuse (verbal abuse, shaming and belittling)
9 ● Constraint and restrictive practices (turning off an electric wheelchair so a person cannot move)
10 ● Financial abuse (charging unnecessary fees, holding onto pensions, wages, etc.)
11 ● Legal or civil abuse (restricted access to services)
12 ● Systemic abuse (denied access to an appropriate service due to perceived support needs)
13 ● Passive neglect (a caregiver's failure to provide adequate food, shelter)
14 ● Lack of education, lack of self-esteem and self-advocacy skills, lack of understanding of social
15 norms and appropriate behavior and communication difficulties are strong contributing factors to
16 the high incidence of abuse among this population.

17 In addition to abuse from people in positions of power, peer abuse is recognized as a significant, if
18 misunderstood, problem. Rates of criminal offense among people with developmental disabilities are also
19 disproportionately high, and it is widely acknowledged that criminal justice systems throughout the world
20 are ill-equipped for the needs of people with developmental disabilities – as both perpetrators and victims
21 of crime.

22 g. Challenging behavior

23 Some people with developmental disabilities exhibit challenging behavior, defined as “culturally abnormal
24 behavior(s) of such intensity, frequency or duration that the physical safety of the person or others is
25 placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to the use of
26 ordinary community facilities”. Common types of challenging behavior include self-injurious behavior (such
27 as hitting, head butting, biting), aggressive behavior (such as hitting others, screaming, spitting, kicking,
28 swearing, hair pulling), inappropriate sexualized behavior (such as public masturbation or groping),
29 behavior directed at property (such as throwing objects and stealing) and stereotyped behaviors (such as
30 repetitive rocking, echolalia or elective incontinence). Such behaviors can be assessed to suggest areas
31 of further improvement, using assessment tools such as the Nisonger Child Behavior Rating Form
32 (NCBRF).

33 Challenging behavior in people with developmental disabilities may be caused by a number of factors,
34 including biological (pain, medication, the need for sensory stimulation), social (boredom, seeking social
35 interaction, the need for an element of control, lack of knowledge of community norms, insensitivity of staff
36 and services to the person's wishes and needs), environmental (physical aspects such as noise and
37 lighting, or gaining access to preferred objects or activities), psychological (feeling excluded, lonely,
38 devalued, labeled, dis-empowered, living up to people's negative expectations) or simply a means of
39 communication. A lot of the time, challenging behavior is learned and brings rewards and it is very often
40 possible to teach people new behaviors to achieve the same aims. Challenging behavior in people with
41 developmental disabilities can often associated with specific mental health problems.

42 Experience and research suggests that what professionals call “challenging behavior” is often a reaction
43 to the challenging environments that those providing services create around people with developmental
44 disabilities. “Challenging behavior” in this context is a method of communicating dissatisfaction with the
45 failure of those providing services to focus on what kind of life makes most sense to the person, and is
46 often the only recourse a developmentally disabled person has against unsatisfactory services or treatment

1 and the lack of opportunities made available to the person. This is especially the case where the services
2 deliver lifestyles and ways of working that are centered on what suits the service provider and its staff,
3 rather than what best suits the person.

4 In general, behavioral interventions or what has been termed applied behavior analysis has been found
5 to be effective in reducing specific challenging behavior. Recently, efforts have been placed on developing
6 a developmental pathway model in the behavior analysis literature to prevent challenging behavior from
7 occurring.

8 h. Societal attitudes

9 Throughout history, people with developmental disabilities have been viewed as incapable and incompetent
10 in their capacity for decision-making and development. Until the Enlightenment in Europe, care and asylum
11 was provided by families and the Church (in monasteries and other religious communities), focusing on
12 the provision of basic physical needs such as food, shelter, and clothing. Stereotypes such as the dim-
13 witted village idiot, and potentially harmful characterizations (such as demonic possession for people with
14 epilepsy) were prominent in social attitudes of the time. The word "bedlam" comes from St. Mary
15 Bethlehem, also called Bethlem Royal Hospital (founded 1247) in London, an asylum, where the public
16 would literally torment the inmates.

17 Early in the twentieth century, the eugenics movement became popular throughout the world. This led to
18 the forced sterilization and prohibition of marriage in most of the developed world and was later used by
19 Hitler as rationale for the mass murder of mentally challenged individuals during the Holocaust. The
20 eugenics movement was later proven to be seriously flawed and in violation of human rights and the
21 practice of forced sterilization and prohibition from marriage was discontinued by most of the developed
22 world by the mid 20th century. I have a mid-1930's Readers Digest in which the main article is rife with
23 sometimes subtle and sometimes blatant appeals to eugenics as the way to improve the world.

24 The movement towards individualism in the 18th and 19th centuries, and the opportunities afforded by the
25 Industrial Revolution, led to housing and care using the asylum model. People were placed by, or removed
26 from, their families (usually in infancy) and housed in large institutions (of up to 3,000 people, although
27 some institutions were home to many more, such as the Philadelphia State Hospital in Pennsylvania which
28 housed 7,000 people through the 1960s), many of which were self-sufficient through the labor of the
29 residents. Some of these institutions provided a very basic level of education (such as differentiation
30 between colors and basic word recognition and numeracy), but most continued to focus solely on the
31 provision of basic needs. Conditions in such institutions varied widely, but the support provided was
32 generally non-individualized, with aberrant behavior and low levels of economic productivity regarded as
33 a burden to society. Heavy tranquilization and assembly line methods of support (such as "birdfeeding"
34 and cattle herding) were the norm, and the medical model of disability prevailed. Services were provided
35 based on the relative ease to the provider, not based on the human needs of the individual.

36 Ignoring the prevailing attitude, Civitans adopted service to the developmentally disabled as a major
37 organizational emphasis in 1952. Their earliest efforts included workshops for special education teachers
38 and day camps for disabled children, all at a time when such training and programs were almost
39 nonexistent.] In the United States, the segregation of people with developmental disabilities wasn't widely
40 questioned by academics or policy-makers until the 1969 publication of Wolf Wolfensberger's seminal work
41 "The Origin and Nature of Our Institutional Models", drawing on some of the ideas proposed by S.G. Howe
42 100 years earlier. This book posited that society characterizes people with disabilities as deviant,
43 sub-human and burdens of charity, resulting in the adoption of that "deviant" role. Wolfensberger argued
44 that this dehumanization, and the segregated institutions that result from it, ignored the potential productive
45 contributions that all people can make to society. He pushed for a shift in policy and practice that

1 recognized the human needs of “retardates” and provided the same basic human rights as for the rest of
2 the population.

3 The publication of this book may be regarded as the first move towards the widespread adoption of the
4 social model of disability in regard to these types of disabilities, and was the impetus for the development
5 of government strategies for desegregation. Successful lawsuits against governments and an increasing
6 awareness of human rights and self-advocacy also contributed to this process, resulting in the passing in
7 the U.S. of the Civil Rights of Institutionalized Persons Act in 1980.

8 From the 1960's to the present, most U.S. states have moved towards the elimination of segregated
9 institutions. Along with the work of Wolfensberger and others including Gunnar and Rosemary Dybwad,
10 a number of scandalous revelations around the horrific conditions within state institutions created public
11 outrage that led to change to a more community-based method of providing services. By the mid-1970s,
12 most governments had committed to de-institutionalization, and had started preparing for the wholesale
13 movement of people into the general community, in line with the principles of normalization. In most
14 countries, this was essentially complete by the late 1990's, although the debate over whether or not to
15 close institutions persists in some states, including Massachusetts.

16 Individuals with developmental disabilities are not fully integrated into society. Person Centered Planning
17 and Person Centered Approaches are seen as methods of addressing the continued labeling and exclusion
18 of socially devalued people, such as people with a developmental disability label, encouraging a focus on
19 the person as someone with capacities and gifts, as well as support needs. This is the approach that is
20 being taken in Idaho for future conservatorship/guardianship proceedings, as detailed later.

21 i. Services and support

22 Today, support services are provided by government agencies (such as MRDD), non-governmental
23 organizations and by private sector providers. Support services address most aspects of life for people with
24 developmental disabilities, and are usually theoretically based in community inclusion, using concepts such
25 as social role valorization and increased self-determination (using models such as Person Centered
26 Planning). Support services are funded through government block funding (paid directly to service
27 providers by the government), through individualized funding packages (paid directly to the individual by
28 the government, specifically for the purchase of services) or privately by the individual (although they may
29 receive certain subsidies or discounts, paid by the government). There also are a number of non-profit
30 agencies dedicated to enriching the lives of people living with developmental disabilities and erasing the
31 barriers they have to being included in their community. The State of Idaho has a website with listed
32 services available, as do organizations such as Disability Rights.

33 j. Education and training

34 Education and training opportunities for people with developmental disabilities have expanded greatly in
35 recent times, with many governments mandating universal access to educational facilities, and more
36 students moving out of special schools and into mainstream classrooms with support.

37 Post-secondary education and vocational training is also increasing for people with these types of
38 disabilities, although many programs offer only segregated “access” courses in areas such as literacy,
39 numeracy and other basic skills. Legislation (such as the UK's Disability Discrimination Act 1995) requires
40 educational institutions and training providers to make “reasonable adjustments” to curriculum and
41 teaching methods in order to accommodate the learning needs of students with disabilities, wherever
42 possible. There are also some vocational training centers that cater specifically to people with disabilities,
43 providing the skills necessary to work in integrated settings, one of the largest being Dale Rogers Training

1 Center in Oklahoma City.

2 k. At-home and community support

3 Many people with developmental disabilities live in the general community, either with family members, in
4 supervised-group homes or in their own homes (that they rent or own, living alone or with flatmates).
5 At-home and community supports range from one-to-one assistance from a support worker with identified
6 aspects of daily living (such as budgeting, shopping or paying bills) to full 24-hour support (including
7 assistance with household tasks, such as cooking and cleaning, and personal care such as showering,
8 dressing and the administration of medication). The need for full 24-hour support is usually associated with
9 difficulties recognizing safety issues (such as responding to a fire or using a telephone) or for people with
10 potentially dangerous medical conditions (such as asthma or diabetes) who are unable to manage their
11 conditions without assistance.

12 In the United States generally, a support worker is known as a Direct Support Professional (DSP). The
13 DSP works in assisting the individual with their ADL's and also acts as an advocate for the individual with
14 a developmental disability, in communicating their needs, self-expression and goals.

15 Supports of this type also include assistance to identify and undertake new hobbies or to access
16 community services (such as education), learning appropriate behavior or recognition of community norms,
17 or with relationships and expanding circles of friends. Most programs offering at-home and community
18 support are designed with the goal of increasing the individual's independence, although it is recognized
19 that people with more severe disabilities may never be able to achieve full independence in some areas
20 of daily life.

21 l. Residential accommodation

22 Some people with developmental disabilities live in residential accommodation (also known as group
23 homes) with other people with similar assessed needs. These homes are usually staffed around the clock,
24 and usually house between 3 and 15 residents. The prevalence of this type of support is gradually
25 decreasing, however, as residential accommodation is replaced by at-home and community support, which
26 can offer increased choice and self-determination for individuals. Some U.S. states still provide institutional
27 care, such as the Texas State Schools. The type of residential accommodation is usually determined by
28 the level of developmental disability and mental health needs. In Idaho, there are no large scale facilities
29 and my recent conversation with the head of IHFA reveals that none are in the pipeline. This means that
30 residential accommodation is mostly certified family homes, sharing roommates and similar methods, or
31 placement in a facility that is not specifically geared to treatment of DD.

32 m. Employment support

33 Employment support usually consists of two types of support:

34 Support to access or participate in integrated employment, in a workplace in the general
35 community. This may include specific programs to increase the skills needed for successful
36 employment (work preparation), one-to-one or small group support for on-the-job training, or
37 one-to-one or small group support after a transition period (such as advocacy when dealing with
38 an employer or a bullying colleague, or assistance to complete an application for a promotion).

39 The provision of specific employment opportunities within segregated business services. Although
40 these are designed as "transitional" services (teaching work skills needed to move into integrated
41 employment), many people remain in such services for the duration of their working life. The types

1 of work performed in business services include mailing and packaging services, cleaning,
2 gardening and landscaping, timber work, metal fabrication, farming and sewing.

3 Workers with developmental disabilities have historically been paid less for their labor than those in the
4 general workforce, although this is gradually changing with government initiatives, the enforcement of
5 anti-discrimination legislation and changes in perceptions of capability in the general community.

6 In the United States, a variety of initiatives have been launched in the past decade to reduce
7 unemployment among workers with disabilities – estimated by researchers at over 60%. Most of these
8 initiatives are directed at employment in mainstream businesses. They include heightened placement
9 efforts by the community agencies serving people with developmental disabilities, as well as by
10 government agencies.

11 Additionally, state-level initiatives are being launched to increase employment among workers with
12 disabilities. In California, the state senate in 2009 created the Senate Select Committee on Autism and
13 Related Disorders. The Committee has been examining additions to existing community employment
14 services, and also new employment approaches. Committee member Lou Vismara, chairman of the MIND
15 Institute at University of California, Davis, is pursuing the development of a planned community for persons
16 with autism and related disorders in the Sacramento region. Another committee member, Michael Bernick,
17 the former director of the state labor department, has established a program at the California state
18 university system, starting at California State University East Bay, to support students with autism on the
19 college level. Other Committee efforts include mutual support employment efforts, such as disability job
20 networks, job boards, and identifying business lines that build on the strengths of persons with disabilities.

21 n. Day services

22 Non-vocational day services are usually known as day centers, and are traditionally segregated services
23 offering training in life skills (such as meal preparation and basic literacy), center-based activities (such
24 as crafts, games and music classes) and external activities (such as day trips). Some more progressive
25 day centers also support people to access vocational training opportunities (such as college courses), and
26 offer individualized outreach services (planning and undertaking activities with the individual, with support
27 offered one-to-one or in small groups).

28 Traditional day centers were based on the principles of occupational therapy, and were created as respite
29 for family members caring for their loved ones with disabilities. This is slowly changing, however, as
30 programs offered become more skills-based and focused on increasing independence.

31 o. Advocacy

32 Advocacy is a burgeoning support field for people with developmental disabilities. Advocacy groups now
33 exist in most jurisdictions, working collaboratively with people with disabilities for systemic change (such
34 as changes in policy and legislation) and for changes for individuals (such as claiming welfare benefits or
35 when responding to abuse). Most advocacy groups also work to support people, throughout the world, to
36 increase their capacity for self-advocacy, teaching the skills necessary for people to advocate for their own
37 needs.

38 p. Other types of support

39 Other types of support for people with developmental disabilities may include:

- 40 ● therapeutic services, such as speech therapy, occupational therapy, physical therapy, massage,

- 1 aromatherapy, art, dance/movement or music therapy
- 2 ● supported holidays
- 3 ● short-stay respite services (for people who live with family members or other unpaid caregivers)
- 4 transport services, such as dial-a-ride or free bus passes
- 5 ● specialist behavior support services, such as high-security services for people with high-level,
- 6 high-risk challenging behaviors
- 7 ● specialist relationships and sex education

8 Programs are set up around the country in hopes to educate individuals with and without developmental
9 disabilities. Studies have been done testing specific scenarios on how what is the most beneficial way to
10 educate people. Interventions are a great way to educate people, but also the most time consuming. With
11 the busy schedules that everybody has, it is found to be difficult to go about the intervention approach.
12 Another scenario that was found to be not as beneficial, but more realistic in the time sense was
13 Psychoeducational approach. They focus on informing people on what abuse is, how to spot abuse, and
14 what to do when spotted. Individuals with developmental disabilities don't only need the support programs
15 to keep them safe, but everybody in society needs to be aware of what is happening and how to help
16 everybody prosper.

17 2. IDAHO STATUTES

18 First of all, to get this out of the way, the appointment of a guardian or conservator does not remove the
19 ability to vote. There are all kinds of bad jokes that could engender, but I will refrain. With the proliferation
20 of absentee voting, that has lead to some interesting situations that facilities should be aware of.

21 Second, there are restrictions/conditions about firearms if someone has an appointed guardian or
22 conservator. Would take too long to run through the federal and state statutes on this in detail, but the
23 Court in making appointments are supposed to determine whether or not the federal statute applies
24 (regarding the federal register of who cannot own, buy, or sell firearms or ammunition) and that
25 determination is supposed to flow through the Idaho State Police to the FBI. Supposed to is the operative
26 phrase. This can get very tricky if the spouse of a person with a guardian/conservator has firearms or
27 ammunition.

28 Third, we are working on merging the DD code into the Idaho Uniform Probate Code because of the many
29 problems that would solve. The two statutes have existed in isolation (other some changes that I have
30 carried in the legislature to provide some cross references) since their inception, but the Courts regularly
31 act as if the two were intertwined.

32 Fourth, both TEPI and the Idaho Supreme Court committees have been working on addressing many
33 areas of conservatorship/guardianship, and especially in the areas of person centered planning, supported
34 decision making. least restrictive means, and so forth.

35 Fifth, the Uniform Laws Commission is currently working on a complete revision of the Uniform Probate
36 Code as if applies to conservatorship/guardianship. I am an Observer on that committee. That is expected
37 to be completed by July of 2017 and therefore might be presented in whole or in part to the Idaho
38 legislature in the 2018 session.

39 Sixth, you need a brief understanding of the *Rogers v. Household Life Insurance Co.* (150 Idaho 735, 250
40 P.3d 786 2011) and *Conway* cases, which I prefer to do orally.

41 The original approach of the State of Idaho, consistent with the factors discussed above, can be seen by
42 the outline of Title 66 State Charitable Institutions, which contains Treatment and Care of the

1 Developmentally Disabled as Chapter 4, especially the earlier chapters 1-8, which are the older law.

- 2 TITLE 66 STATE CHARITABLE INSTITUTIONS
- 3 CHAPTER 1 STATE HOSPITALS
- 4 CHAPTER 2 INSANE ASYLUMS -- [REPEALED]
- 5 CHAPTER 3 HOSPITALIZATION OF MENTALLY ILL
- 6 CHAPTER 4 TREATMENT AND CARE OF THE DEVELOPMENTALLY DISABLED
- 7 CHAPTER 5 STATE ASYLUM AND SANITARIUM FUND FOR PATIENTS
- 8 CHAPTER 6 DECLARATIONS FOR MENTAL HEALTH TREATMENT
- 9 CHAPTER 7 COMMITMENT TO IDAHO STATE SCHOOL AND COLONY -- [REPEALED]
- 10 CHAPTER 8 STERILIZATION LAW -- [REPEALED]
- 11 CHAPTER 9 IDAHO VETERANS' HOME
- 12 CHAPTER 10 IDAHO TUBERCULOSIS HOSPITAL
- 13 CHAPTER 11 FUNDS OF CHARITABLE INSTITUTIONS
- 14 CHAPTER 12 INTERSTATE COMPACT ON MENTAL HEALTH
- 15 CHAPTER 13 IDAHO SECURITY MEDICAL PROGRAM

16 The legislative intent in enacting Title 66 Chapter 4, in 1982, significantly amended in 2010, is:

17 66-401. LEGISLATIVE INTENT. It is hereby declared by the legislature of the state of Idaho in
18 enacting chapter 4, title 66, Idaho Code, that the citizens of Idaho who have developmental
19 disabilities are entitled to be diagnosed, cared for, and treated in a manner consistent with their
20 legal rights in a manner no more restrictive than for their protection and the protection of society,
21 for a period no longer than reasonably necessary for diagnosis, care, treatment and protection, and
22 to remain at liberty or be cared for privately except when necessary for their protection or the
23 protection of society. Recognizing that every individual has unique needs and differing abilities, it
24 is the purpose of the provisions of this chapter to promote the general welfare of all citizens by
25 establishing a system which permits partially disabled and disabled persons to participate as fully
26 as possible in all decisions which affect them, which assists such persons in meeting the essential
27 requirements for their physical health and safety, protecting their rights, managing their financial
28 resources, and developing or regaining their abilities to the maximum extent possible. The
29 provisions of this chapter shall be liberally construed to accomplish these purposes.

30 This general intent needs to be recognized in reading other statutes and in looking generally at Idaho C&G
31 statutes. One major point to be aware of is that this statute, originally enacted in 1982, has no cross
32 references in general to the Idaho Uniform Probate Code, enacted in 1971 and effective January 1, 1972.

33 For Idaho, the relevant definition of Developmental Disability is in 66-402:

- 34 (5) "Developmental disability" means a chronic disability of a person which appears before the age
35 of twenty-two (22) years of age and:
- 36 (a) Is attributable to an impairment, such as intellectual disability, cerebral palsy, epilepsy,
37 autism or other condition found to be closely related to or similar to one (1) of these
38 impairments that requires similar treatment or services, or is attributable to dyslexia
39 resulting from such impairments; and
 - 40 (b) Results in substantial functional limitations in three (3) or more of the following areas of
41 major life activity: self-care, receptive and expressive language, learning, mobility,
42 self-direction, capacity for independent living, or economic self-sufficiency; and
 - 43 (c) Reflects the need for a combination and sequence of special, interdisciplinary or generic
44 care, treatment or other services which are of lifelong or extended duration and individually

1 planned and coordinated.

2 Further in that section:

3 (9) "Lacks capacity to make informed decisions" means the inability, by reason of developmental
4 disability, to achieve a rudimentary understanding of the purpose, nature, and possible risks and
5 benefits of a decision, after conscientious efforts at explanation, but shall not be evidenced by
6 improvident decisions within the discretion allowed nondevelopmentally disabled individuals.

7 (10) "Likely to injure himself or others" means:

8 (a) A substantial risk that physical harm will be inflicted by the respondent upon his own
9 person as evidenced by threats or attempts to commit suicide or inflict physical harm on
10 himself; or

11 (b) A substantial risk that physical harm will be inflicted by the respondent upon another as
12 evidenced by behavior which has caused such harm or which places another person or
13 persons in reasonable fear of sustaining such harm; or

14 (c) That the respondent is unable to meet essential requirements for physical health or
15 safety.

16 (11) "Manage financial resources" means the actions necessary to obtain, administer and dispose
17 of real, personal, intangible or business property, benefits and/or income.

18 (12) "Meet essential requirements for physical health or safety" means the actions necessary to
19 provide health care, food, clothing, shelter, personal hygiene and/or other care without which
20 serious physical injury or illness would occur.

21 Venue for court proceedings is straightforward:

22 66-403. COURT JURISDICTION. Judicial proceedings authorized by the provisions of this chapter
23 shall be had in the district court of the county where the respondent resides or is found.

24 Proceedings for appointment are as follows, which was not modified after 1982 until 2009 and 2013, and
25 which remains unintegrated with the probate code in Title 15, Chapter 5.

26 66-404. PROCEEDINGS FOR APPOINTMENT OF GUARDIANS AND CONSERVATORS. (1) A
27 person with a developmental disability or any person interested in his welfare may petition for a
28 finding of legal disability or partial legal disability and appointment of a guardian and/or conservator.

29 (2) The petition shall:

30 (a) State the names and addresses of the persons entitled to notice under subsection (4)
31 of this section;

32 (b) Describe the impairments showing the respondent is developmentally disabled, the
33 respondent's ability to receive, evaluate and communicate information, and the
34 respondent's ability to manage financial resources and meet essential requirements for
35 physical health or safety;

36 (c) State the nature and scope of guardianship and/or conservatorship services sought;

37 (d) Describe the respondent's financial condition, including significant assets, income and
38 ability to pay for the costs of judicial proceedings; and

39 (e) State if the appointment is made by will pursuant to section 15-5-301, Idaho Code, and
40 the name(s) and address(es) of the person(s) named in the will to be guardian.

41 (3) Upon filing of a petition, the court shall set a date for a hearing, appoint an attorney to represent
42 the respondent in the proceedings unless the respondent has an attorney, and authorize an

1 evaluation committee to examine the respondent, interview the proposed guardians and/or
2 conservators and report to the court in writing. The report shall contain:

- 3 (a) A description of the nature and extent of the evaluation and the alleged impairments,
4 if any;
- 5 (b) A description of the respondent's mental, emotional and physical condition; educational
6 status; and adaptive and social skills;
- 7 (c) A description of the services, if any, needed by the respondent to meet essential
8 requirements for physical health and safety, and/or manage financial resources;
- 9 (d) A recommendation regarding the type and extent of guardianship or conservatorship
10 assistance, if any, required by the respondent and why no less restrictive alternative would
11 be appropriate;
- 12 (e) An opinion regarding the probability that the extent of the respondent's disabilities may
13 significantly lessen, and the type of services or treatment which may facilitate improvement
14 in the respondent's behavior, condition, or skills;
- 15 (f) The respondent's preference, if any, regarding the person or persons to be appointed
16 as guardian and/or conservator;
- 17 (g) The suitability of the person or persons proposed as guardian and/or conservator; and
18 (h) The signature of each member of the evaluation committee with a statement of
19 concurrence or nonconcurrence with the findings and any dissenting opinions or other
20 comments of the members.

21 (4) Notice of the time and place of the hearing on the petition together with a copy of the petition
22 shall be served no less than ten (10) days before the hearing on:

- 23 (a) The respondent;
- 24 (b) The respondent's spouse, parents and adult children, or if none, the respondent's
25 closest relative, if any can be found; and
- 26 (c) Any person who is currently serving as guardian, conservator or who is providing care
27 for the respondent.

28 Notice shall be served personally if the person to be served can be found within the state. If the
29 person to be served cannot be found within the state, service shall be accomplished by registered
30 mail to such person's last known address.

31 (5) The respondent is entitled to be present at the hearing in person, to present evidence, call and
32 cross-examine witnesses, and to see or hear all evidence in the proceeding.

33 (6) At the hearing the court shall:

- 34 (a) Determine whether the respondent has a developmental disability;
- 35 (b) Evaluate the respondent's ability to meet essential requirements for physical health or
36 safety and manage financial resources;
- 37 (c) Evaluate the ability of the proposed guardian and/or conservator to act in the
38 respondent's best interests to manage the respondent's financial resources and meet
39 essential requirements for the respondent's physical health or safety;
- 40 (d) Determine the nature and scope of guardianship or conservatorship services necessary
41 to protect and promote the respondent's well-being; and
- 42 (e) Evaluate the ability of the respondent or those legally responsible to pay the costs
43 associated with the judicial proceedings and fix responsibility therefor.

44 (7) No individual shall be appointed as guardian or conservator of an incapacitated person unless
45 all of the following first occurs:

- 46 (a) The proposed guardian or conservator has submitted to and paid for a criminal history
47 and background check conducted pursuant to section 56-1004A(2) and (3), Idaho Code;
- 48 (b) In the case of a petition for guardianship and pursuant to an order of the court so
49 requiring, any individual who resides in the incapacitated person's proposed residence has
50 submitted, at the proposed guardian's expense, to a criminal history and background check
51 conducted pursuant to section 56-1004A(2) and (3), Idaho Code;

1 (c) The findings of such criminal history and background checks have been made available
2 to the evaluation committee by the department of health and welfare; and
3 (d) The proposed guardian or conservator provided a report of his or her civil judgments
4 and bankruptcies to the evaluation committee and all others entitled to notice of the
5 guardianship or conservatorship proceeding pursuant to subsection (4) of this section.
6 (8) The provisions of paragraphs (a) and (d) of subsection (7) of this section shall not apply to an
7 institution nor to a legal or commercial entity.
8 (9) Each proposed guardian and conservator and each appointed guardian and conservator shall
9 immediately report any change in his or her criminal history and any material change in the
10 information required by subsection (7) of this section to the evaluation committee, all others entitled
11 to notice of the guardianship or conservatorship proceeding pursuant to subsection (4) of this
12 section and to the court.

13 There are major differences between the DD code and the Probate code in the procedure for appointment.

14 First, unlike the Probate code, there is no appointment of a Court Visitor. Instead, there is an
15 Evaluation Committee through Health&Welfare.

16 Second, there is not an appointment of a Guardian ad Litem attorney. Instead, there is the
17 appointment of an attorney by the Court unless the person has their own attorney. Despite that, I
18 have routinely been appointed as a Guardian ad Litem in DD cases. I have written articles and
19 done seminars on the differences, especially ethically, between an attorney for a person in
20 guardianship and a Guardian ad Litem. And some statutes refer to “an attorney with the powers
21 of a Guardian ad Litem”, which really muddies the waters.

22 Third, although the criminal background check provisions apply in both the DD code and the
23 Probate Code, the requirement of the online training created by the court system only applies to
24 the Probate Code procedures, not DD.

25 §66-405 is extremely important to understand in treating developmentally disabled individuals. It is crucial
26 to understand this section and especially what it does not cover. This section contains what are commonly
27 called the “Baby Doe Regs”. The accompanying Addendum has an extensive history of the Baby Doe Regs
28 and also an extensive discussion of their effect in the neonatal area primarily. However, it is very relevant
29 to DD law, and to treatment generally, because much of the terminology and principles resulting from the
30 Baby Doe case and Regs has ended up in Idaho’s DD act and in the Idaho Medical Consent and Natural
31 Death Act.

32 66-405. ORDER IN PROTECTIVE PROCEEDINGS. (1) If it is determined that the respondent
33 does not have a developmental disability but appears in need of protective services, the court may
34 cause the proceeding to be expanded or altered for consideration under the uniform probate code.
35 (2) If it is determined that the respondent is able to manage financial resources and meet essential
36 requirements for physical health or safety, the court shall dismiss the petition.
37 (3) If it is determined that the respondent has a developmental disability and is unable to manage
38 some financial resources or meet some essential requirements for physical health or safety, the
39 court may appoint a partial guardian and/or partial conservator on behalf of the respondent. An
40 order establishing partial guardianship or partial conservatorship shall define the powers and duties
41 of the partial guardian or partial conservator so as to permit the respondent to meet essential
42 requirements for physical health or safety and to manage financial resources commensurate with
43 his ability to do so, and shall specify all legal restrictions to which he is subject. A person for whom
44 a partial guardianship or partial conservatorship has been appointed under this chapter retains all
45 legal and civil rights except those which have by court order been limited or which have been

1 specifically granted to the partial guardian or partial conservator by the court.

2 (4) If it is determined that the respondent has a developmental disability and is unable to manage
3 financial resources or meet essential requirements for physical health or safety even with the
4 appointment of a partial guardian or partial conservator, the court may appoint a total guardian
5 and/or total conservator.

6 (5) In the event that more than one (1) person seeks to be appointed guardian and/or conservator,
7 the court shall appoint the person or persons most capable of serving on behalf of the respondent;
8 the court shall not customarily or ordinarily appoint the department or any other organization or
9 individual, public or private, that is or is likely to be providing services to the respondent. If an
10 appointment of a guardian is made by will pursuant to section 15-5-301, Idaho Code, such
11 appointment shall be entitled to preference as the guardian under this chapter, if the person so
12 appointed by will is capable of serving on behalf of the respondent and the court finds that it is not
13 in the best interests of the respondent to appoint a different person as guardian.

14 (6) Subject to the limitations of the provisions of subsection (7) of this section, guardians or
15 conservators may have any of the duties and powers as provided in sections 15-5-312(1)(a)
16 through (d), 15-5-424 and 15-5-425, Idaho Code, and as specified in the order. A guardian shall
17 be required to report to the court at least annually on the status of the person with a developmental
18 disability. A conservator shall be required to file with the court an inventory within ninety (90) days
19 of appointment, an accounting at least annually, and a final accounting at the termination of the
20 appointment of the conservator. All required inventories, accountings and reports shall be under
21 oath or affirmation and shall comply with the Idaho supreme court rules. The court may require a
22 conservator to submit to a physical check of the estate in his control, to be made in any manner
23 the court may specify.

24 (7) No guardian appointed under this chapter shall have the authority to refuse or withhold consent
25 for medically necessary treatment when the effect of withholding such treatment would seriously
26 endanger the life or health and well-being of the person with a developmental disability. To withhold
27 or attempt to withhold such treatment shall constitute neglect of the person and be cause for
28 removal of the guardian. No physician or caregiver shall withhold or withdraw such treatment for
29 a respondent whose condition is not terminal or whose death is not imminent. If the physician or
30 caregiver cannot obtain valid consent for medically necessary treatment from the guardian, he shall
31 provide the medically necessary treatment as authorized by section 39-4504(1)(i), Idaho Code.

32 (8) A guardian appointed under this chapter may consent to withholding or withdrawal of artificial
33 life-sustaining procedures, only if the respondent:

34 (a) Has an incurable injury, disease, illness or condition, certified by the respondent's
35 attending physician and at least one (1) other physician to be terminal such that the
36 application of artificial life-sustaining procedures would not result in the possibility of saving
37 or significantly prolonging the life of the respondent, and would only serve to prolong the
38 moment of the respondent's death for a period of hours, days or weeks, and where both
39 physicians certify that death is imminent, whether or not the life-sustaining procedures are
40 used; or

41 (b) Has been diagnosed by the respondent's attending physician and at least one (1) other
42 physician as being in a persistent vegetative state which is irreversible and from which the
43 respondent will never regain consciousness.

44 (9) Any person who has information that medically necessary treatment of a respondent has been
45 withheld or withdrawn may report such information to adult protective services or to the Idaho
46 protection and advocacy system for people with developmental disabilities, which shall have the
47 authority to investigate the report and in appropriate cases to seek a court order to ensure that
48 medically necessary treatment is provided.

49 If adult protective services or the protection and advocacy system determines that withholding of
50 medical treatment violates the provisions of this section, they may petition the court for an ex parte
51 order to provide or continue the medical treatment in question. If the court finds, based on affidavits

1 or other evidence, that there is probable cause to believe that the withholding of medical treatment
2 in a particular case violates the provisions of this section, and that the life or health of the patient
3 is endangered thereby, the court shall issue an ex parte order to continue or to provide the
4 treatment until such time as the court can hear evidence from the parties involved. Petitions for
5 court orders under this section shall be expedited by the courts and heard as soon as possible. No
6 bond shall be required of a petitioner under this section.

7 (10) No partial or total guardian or partial or total conservator appointed under the provisions of this
8 section may without specific approval of the court in a proceeding separate from that in which such
9 guardian or conservator was appointed:

10 (a) Consent to medical or surgical treatment the effect of which permanently prohibits the
11 conception of children by the respondent unless the treatment or procedures are necessary
12 to protect the physical health of the respondent and would be prescribed for a person who
13 does not have a developmental disability;

14 (b) Consent to experimental surgery, procedures or medications; or

15 (c) Delegate the powers granted by the order.

16 I am skipping over much detail which is mainly technical. The next relevant sections are:

17 66-409. **AUTHORITY TO ADMIT DEVELOPMENTALLY DISABLED PERSONS.** The head of any
18 facility licensed under state law is authorized to admit for observation, diagnosis, care or treatment
19 any developmentally disabled person for services provided by that facility.

20 **66-412. RIGHTS IN FACILITIES. (1) Every developmentally disabled person admitted to any**
21 **facility shall be entitled to humane care and treatment.**

22 **(2) A developmentally disabled person shall not be put in isolation. Mechanical restraints**
23 **shall not be applied unless it is determined to be necessary for the safety of that person or**
24 **the safety of others. Every use of a mechanical restraint, or time out for therapeutic**
25 **purposes, and the reasons therefore [therefor], shall be made a part of the permanent**
26 **record of the person under the signature of the facility head.**

27 **(3) Every developmentally disabled person has the following rights:**

28 (a) **To be free from mental and physical abuse including that which arises from acts**
29 **of negligence;**

30 (b) **To reside in the environment or setting that is least restrictive of personal**
31 **liberties in which appropriate treatment can be provided;**

32 (c) **To communicate by sealed mail, telephone, or otherwise with persons inside or**
33 **outside the facility, to have access to reasonable amounts of letter writing material**
34 **and postage and to have access to private areas to make telephone calls and receive**
35 **visitors;**

36 (d) **To receive visitors at all reasonable times and to associate freely with persons**
37 **of his own choice;**

38 (e) **To wear his own clothes, keep and use his own personal possessions including**
39 **toilet articles, keep and be allowed to spend a reasonable sum of his own money for**
40 **personal expenses and small purchases, and have access to individual storage**
41 **space for his own use;**

42 (f) **To have free access to established procedures to voice grievances and to**
43 **recommend changes in the policies and/or services being offered at the facility;**

44 (g) **To practice his religion;**

45 (h) **To be informed of his medical and habilitative condition, of services available in**
46 **the facility and the charges therefor;**

47 (i) **To have reasonable access to all records concerning himself; and**

1 (j) Unless limited by prior court order, to exercise all civil rights, including the right
2 to dispose of property, except property described in subsection (e) of this section,
3 execute instruments, make purchases, enter into contractual arrangements, and
4 vote.

5 (4) Adult and emancipated minor developmentally disabled individuals or a parent or guardian with
6 authority to consent to treatment with respect to the minor child or ward, shall have the right to
7 refuse specific modes of treatment or habilitation. The head of a facility may deny the right to
8 refuse treatment or habilitation only in cases of emergency or when a court has determined that
9 an adult or emancipated minor lacks the capacity to make informed decisions about treatment and
10 there is no guardian with authority to consent to treatment. A statement explaining the reasons for
11 any such denial shall immediately be entered in the individual's permanent record and in the case
12 of respondents committed under section 66-406, Idaho Code, copies of the statement shall be sent
13 to the committing court, the respondent's attorney and either the respondent's spouse, guardian,
14 adult next of kin or friend.

15 (5) A list of the rights contained in this section and section 66-413, Idaho Code, shall be
16 prominently posted in all facilities and explained as far as possible to each developmentally
17 disabled individual.

18 3. PRACTICAL CONSIDERATIONS FROM THE FOREGOING

19 First, both the Probate Code and the DD Code are very clear that alternatives to appointment of a guardian
20 and/or conservator should be considered first. This includes use of trusts, powers, and so forth to avoid
21 needing a formal appointment. This also may include Supported Decision Making, which is:

22 A series of relationships, practices, arrangements, and agreements, or more or less formality and
23 intensity, designed to assist an individual with a disability to make and communicate to others
24 decisions about the individual's life. From: Robert Dinerstein, *Implementing Legal Capacity Under*
25 *Article 12 of the UN Convention of the Rights of Persons with Disabilities: The Difficult Road from*
26 *Guardianship to Supported Decision Making*, 19 Human Rights Brief 8, 10 (Winter 2012)

27 This is the creation of a team of individuals, which can include family members, friends, and professionals,
28 who commit to help explain to the person in simple language about possible choices and the impact of
29 those choices. Usually, the person with a disability and the team will create a Supported Decision Making
30 Agreement. The Agreement uses Person Centered Planning, which is working directly with the person who
31 is the focus of the plan to ensure that plans are based on an understanding of the person's unique
32 priorities and desires. Even in situations without Supported Decision Making being directly used, planning
33 should always be Person Centered. You should be prepared to deal with this method and have procedures
34 in place that recognize Supported Decision Making Agreements and how to deal with them in making
35 medical decisions.

36 Second, if there is a need to make an appointment, the least restrictive means should be used. Limited
37 guardianship and/or conservatorship should be the norm, not the exception. This is already in the two
38 codes, but we are working on ways to make this happen in the real world. Absent good cause, a person
39 has the right to make decisions, including medical decisions. The fact that some may be developmentally
40 disabled does not automatically remove their ability to make medical decisions. The Baby Doe regs
41 discussed above apply only when there is an actual guardianship, and then only to decisions by the
42 guardian. Decisions by the person with disability are not covered by those provisions in 66-405.

43 Third, be aware that, under current practice, there is a great tendency to have a full appointment even
44 when the person has the ability to make decisions in many areas. Therefore, many guardians actually treat
45 the guardianship as if it were a limited guardianship, allowing the ward to make many of their own

1 decisions. This can create ambiguities when you are dealing with the person without the guardian present.
2 You should have procedures in place whenever a person under guardianship is either admitted or providing
3 information to ascertain whether a guardianship is in place, if so what form of guardianship is in place
4 (limited or general), and if possible to discuss with the guardian whether the ward actually has the ability
5 to make some, all, or no medical decisions. The guardian, like a medical agent under a durable power of
6 attorney for health care, is to follow the known wishes of the ward, including their latest authentic
7 expressed wishes.

8 Fourth, do not treat the POST as a magic document. It is simply a medical decision document that fits in
9 the series. The latest authentic expression is what controls, so if a later document or statement by the
10 person conflicts with the POST, that later document or statement controls. Also, when working with people,
11 make sure that they really understand what a POST is. Too many are made without a correct
12 understanding of the effects of a POST.

13 Fifth, facilities cannot require the execution of a POST or DNR as a condition of admission. Period. I see
14 this far too often.

15 Sixth, the fact that a person is developmentally disabled does not make any initial difference in how they
16 should be treated. Like any other person, there should be an assessment of their ability to make and/or
17 communicate a medical decision. DD persons can make Wills, execute medical and financial powers, sign
18 consents, choose living conditions and places, etc. unless specifically limited by law. Further, a person is
19 developmentally disabled legally only if so determined. Do not make this diagnosis on your own.

20 Seventh, involve the person even if they have a guardian. Include them to the maximum extent feasible
21 and reasonable in all discussions, decisions, explanations. Especially, do not act like they are deaf and
22 dumb. Make eye contact, ask them questions, and treat them with dignity and respect. Work with the
23 guardian to understand what limitations, but also what strengths and abilities, the person has. Concentrate
24 on what they can do, not what they can't.