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ADDENDUM – THE BABY DOE REGS

This addendum is taken largely from an article in the Ochsner Journal by Michael White, MD, in the winter of 2011. The issue of the Baby Doe Regs geared originally to the neonatal side, but the principles apply to developmental disability cases since the terms and conditions in the Baby Doe Regs have largely been replicated in the Idaho DD statute (Senate Bill 1090, 2017 Session) and IDAPA and also to a lesser degree in the Medical Consent and Natural Death Act (title 39, chapter 45) and therefore apply not just to the very young, but also to a vast number of others. Also note that there were two Baby Does - one unidentified in any way, born in 1982, and the other identified as Baby Jane Doe, born in 1983.

An unidentified infant, now known as Baby Doe, was born April 9, 1982, in Bloomington, Indiana. This birth and death has had a major effect in the management of infants born with disabilities. The regulations resulting from this case now insert themselves into all decisions regarding management of newborn infants, particularly those decisions made for infants born at the cusp of viability, and in the treatment of the developmentally disabled under certain circumstances. The following is an exhaustive history of the case both legally and in Congress.

Historically, government authority has avoided intrusion into the sphere of influence surrounding the perceived right of the family in consultation with physicians to make decisions regarding the care of their child. All this changed when the obstetrician delivering a child born with Down syndrome and tracheoesophageal fistula recommended that the family not pursue treatment, citing a 50% chance of surviving surgical repair and bleak prospects if the child survived. Advised of the family's decision not to provide consent for repair of the tracheoesophageal fistula, the family physician and a local pediatrician strongly opposed this plan. Their concern stemmed from their belief that the prognosis for a good medical outcome after surgical repair of an abnormal esophagus based on contemporary management was much more favorable than the family was led to believe. These physicians enrolled several attorneys and enlisted couples willing to adopt the child in an effort to prevent the child's imminent death. The case was presented to local courts, appealing for a declaration of neglect under Indiana's Child in Need of Services statute. The courts chose to follow contemporary precedent, deferring to the parents' decision. The case was then prepared for presentation to U.S. Supreme Court Justice John Paul Stevens. Baby Doe died of dehydration and pneumonia at 6 days of age on April 15, before the case could be heard.

Upon learning of the case of Baby Doe, U.S. Surgeon General C. Everett Koop was outraged. His opinion was driven by conservative Christian ideals and his own experience of nearly 100% success with the repair of tracheoesophageal fistulas while Surgeon in Chief at the Children's Hospital of Philadelphia. He opined that the decision to forego treatment could only be based on discrimination because of the diagnosis of Down syndrome and the family's concern for future disability related to this diagnosis. Koop began a campaign to prevent this perceived discrimination against children with disabilities leading to the withholding of medical intervention. After he enlisted

the resources of the Reagan administration, controversial rules were soon in place, promulgated under the Americans With Disabilities Act to prevent such perceived abuses.

Citing “heightened public concern” in the aftermath of the Baby Doe incident, on May 18, 1982, the director of the Department's Office of Civil Rights, in response to a directive from the President, “remind[ed]” healthcare providers receiving federal financial assistance that newborn infants with handicaps such as Down syndrome were protected by the Americans With Disabilities Act. This notice was followed on March 7, 1983, by an Interim Final Rule contemplating a “vigorous federal role” for the enforcement of these rules.

This initial effort to prevent the perceived withholding of care from handicapped infants solely on the basis of their disability included the creation of Baby Doe Hotlines and federally mandated posting of notices in all hospital nurseries that included the instruction “Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact: Handicapped Infant Hotline” and a telephone number for the US Department of Health and Human Services (HHS).

Surgeon General Koop soon found an appropriate forum for voicing his concerns after the birth of a child diagnosed with spina bifida, microcephaly, and hydrocephalus in Port Jefferson, Long Island, on October, 15, 1983. The infant, known as Baby Jane Doe, was promptly transferred to Stony Brook Medical Center for medical management, where the parents decided against intervention after receiving contradictory medical opinions. HHS became involved in this case after a Baby Doe Hotline call reported concerns regarding the withholding of treatment, spurring Koop into action. Subsequent unsuccessful efforts to subpoena medical records and compel medical intervention through court action are well documented.

Meanwhile, several professional organizations challenged the regulations mandating the creation of the Baby Doe Hotlines, reaching the courts as *Bowen vs American Hospital Association*. In 1986, the US Supreme Court struck down the first rules establishing the Baby Doe Hotlines under the Americans With Disabilities Act.

Despite the setback of the court decision regarding the initial regulations promulgated under the Americans With Disabilities Act, the efforts of Koop and the Reagan administration continued. The results of these efforts are known as the Baby Doe Rules, which survived congressional review as part of the 1988 Revision of the Child Abuse Prevention and Treatment Act (CAPTA).

This act includes the following provisions:

The term “withholding of medically indicated treatment” means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's (or physicians') reasonable medical judgment any of the following circumstances apply:

- (i) The infant is chronically and irreversibly comatose;
- (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise

be futile in terms of the survival of the infant; or
(iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

These rules seem unequivocal, and as recently as 2004, Robertson claimed that any controversy surrounding the Baby Doe rules is dead and that the rules are absolute. He argued that the regulations leave no room for interpretation and include no allowance for parental concerns. He followed by examining the difficulties this interpretation imposes for families and caretakers when faced with the prospect of an infant likely to require lifelong care with little or no meaningful interaction with the environment.

The Baby Doe rules appear to allow little room for interpretation. They seem to unequivocally restrict the ability of families and physicians to incorporate quality-of-life considerations when making decisions for an infant, which most authorities continue to accept as the standard of care. The American Medical Association formally endorsed the quality-of-life standard prior to the Baby Doe case, as summarized by this statement:

In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness, or advanced age, quality of life is a factor to be considered in determining what is best for the individual.

In caring for defective infants the advice and judgment of the physician should be readily available, but the decision as to whether to treat a severely defective infant and exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks, and limits of any proposed care; how the potential for human relationship is affected by the infant's condition; and relevant information and answers to their questions.

Paradoxically, the position that parents and physicians should make all decisions for infants was also supported by the contemporaneous recommendations of the President's Commission for the Study of Ethical Problems in Medicine, first outlined in its 1982 report "Making Health Care Decisions." This document from Reagan's own appointees, selected to provide guidance on ethical issues during his tenure, reviewed the process of guidance in making decisions for those unable to speak for themselves. In cases where the patient is unable to participate in the medical decision-making process and there is no previous history to provide insight into how the incapacitated person might wish to proceed, the commission supported the concept of the best interests standard:

Decisionmaking guided by the best interests standard requires a surrogate to do what, from an objective standpoint, appears to promote a patient's good without reference to the patient's actual or supposed preferences. This does not mean the surrogate must choose the means the practitioner thinks is "best" for promoting the patient's well-being, but only a means reasonably likely to achieve that goal.

This concern was addressed specifically for end-of-life decisions the following year in the commission's report "Deciding to Forego Life-Sustaining Treatment." This report stated that surrogate decisions made when the patient is incapable of making his or her own decisions for any reason should first rely on the concept of substituted judgment where the "standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose." The report noted that the appropriate means of decisionmaking should rely

first on any previously cited preferences of the now-incapacitated patient. The commission considered circumstances in which “some patients have never been competent; thus, their subjective wishes, real or hypothetical, are impossible to discern with any certainty” and invoked the best interests standard for this situation that best describes the circumstance of a parent making decisions for a newborn infant. “In these situations, surrogate decision makers will be unable to make a valid substituted judgment; instead, they must try to make a choice for the patient that seeks to implement what is in that person's best interests by reference to more objective, societally shared criteria.”

The commission specifically cited factors such as “relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained” and stated that the “impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates.”

This same report directly addressed the decision-making process for critically ill neonates. “Parents should be the surrogates for a seriously ill newborn unless they are disqualified by decision-making incapacity, an unresolvable disagreement between them, or their choice of a course of action that is clearly against the infant's best interests.” Recognizing the contemporaneous concern regarding Baby Doe, commission members also noted, “infants should receive all therapies that are clearly beneficial to them. For example, an otherwise healthy Down syndrome child whose life is threatened by a surgically correctable complication should receive the surgery because he or she would clearly benefit from it.”

After identifying the parents as the appropriate surrogate decisionmaker in almost all circumstances, the commission commented on the importance of appropriate information as the basis for making decisions and the responsibility of physicians: “Decisionmakers should have access to the most accurate and up-to-date information as they consider individual cases.” This statement recognizes that controversial decisions sometimes reflect information that is not up to date or complete, as implied in the case of Baby Doe when the information that led to the decision to withhold permission to repair the esophageal atresia was provided by the presumptively less informed obstetrician. To ensure that decisions to forego therapy are approached in a consistent fashion, the commission recommended that a committee be created within each institution providing care for infants and be tasked with the review of all decisions to forego therapy or cases in which opinions regarding appropriate care might diverge. Commissioners emphasized the need for institutional introspection into this process, recommending not only prospective evaluation when issues arise, but also a formal process for “retrospective review of decisions when life-sustaining treatment for an infant might be foregone or when parents and providers disagree about the correct decision for an infant. Certain categories of clearly futile therapies could be explicitly excluded from review.”

The commission also recognized the potential for controversy regarding appropriate care of an ill neonate and suggested the following guidance: “The best interests of an infant should be pursued when those interests are clear. The policies should allow for the exercise of parental discretion when a child's interests are ambiguous.” The commission also acknowledged the necessary roles of the law and judicial intervention: “Decisions should be referred to public agencies (including courts) for review when necessary to determine whether parents should be disqualified as decisionmakers and, if so, who should decide the course of treatment that would be in the best interests of their child.”

Finally, the commission directly addressed the role of government in surrogate decisions for newborns, appearing to rebuke the efforts by the Reagan administration to regulate neonatal decisionmaking. This report specifically stated, “The legal system has various—though limited—roles in ensuring that seriously ill infants receive the correct care.” One such role is served by the civil courts that consider cases in which the parents may not appropriately represent the best interests of the child and appoint an appropriate surrogate. The commission also supported the role of the state for investigation of suspected child neglect or abuse but decried “using financial sanctions against institutions to punish an ‘incorrect’ decision in a particular case,” doubting the usefulness and pointing out that such action might “actually penalize other patients and providers in an unjust way.” This last statement was a direct rebuke of the contemporaneous impending formulation of the Baby Doe rules conceived under CAPTA and enforceable only by withholding federal funding for anti-child abuse programs.

The American Academy of Pediatrics (AAP), which organized the Infant Bioethics Task Force and Consultants to consider the ethics of neonatal care, also supported the tradition of the best interests standard. Recognizing the contemporary controversy and following the arguments from the President’s Commission, as well as making an effort to influence the federal regulations still under review, the task force issued the Guidelines for Infant Bioethics Committees. In this document, clearly directed at minimizing the effect of federal regulatory efforts and supporting the President’s Commission, the AAP recommended that “each hospital that provides care for infants give serious consideration to the role an Infant Bioethics Committee may play in aiding decisionmaking about the care of seriously ill infants.” Furthermore, the AAP specifically identified one of the functions of the committee as “offering consultation and review on treatment decisions regarding critically ill infants, especially when the foregoing of life sustaining treatment is being considered.” The guidelines promoted both prospective review of all cases in which questions arise and retrospective review of all cases in which a decision is made to withdraw support.

Although most of the AAP statement was simply a proposal for how such committees should function, it was also an effort to document a consistent approach to end-of-life decisions in the withdrawal of support for infants (defined in this document as those under 2 years of age). In a nod to the Reagan administration’s then-impending regulatory efforts, the statement emphasized the legal responsibilities for reporting suspected instances of child neglect or abuse. Recognizing the volatile contemporaneous legal environment, the statement also pointed out the importance of indemnification for committee members to protect them from potential legal action.

Recommendations for making surrogate decisions using the best interests standard are clearly outside the realm of considerations acceptable under the 3 specific guidelines in the Baby Doe rules. The rule utilitarian approach advanced by the Baby Doe rules—driven by the belief that life is preeminent and no other considerations are pertinent—conflicts directly with the approach of the best interests standard cited by the President’s Commission and endorsed by the AAP. This conflict has placed pediatricians, neonatologists, and others providing care for newborn infants in the position of choosing to follow either federal rules that appear unequivocal or the guidance of the AAP and tradition in upholding the best interests standard.

The conflict is further complicated by the stand of the AAP, which maintains that the best interests standard can be reconciled with the Baby Doe rules based on a very liberal and, most would argue, incorrect interpretation of the phrase “. . .when, in the treating physician’s (or physicians’) reasonable medical judgment. . . .” The AAP contends that this phrase allows broad discretion in deciding which infants might fall into the 3 categories exempted from the rules, thus supporting the best interests

standard as the basis for decisionmaking in almost all circumstances. This debate fills the literature because the rules were promulgated primarily by federal guidance documents interpreting the rules. In addition, a large body of literature attempts to reconcile the apparent inflexibility of the Baby Doe rules with the widely held tradition of acting in the best interests of the infant based on careful consideration by the family and other caretakers.

Continuing to support the best interests standard and maintaining that it does not conflict with the Baby Doe rules, the AAP again addressed end-of-life issues for children in "Guidelines on Foregoing Life-Sustaining Medical Treatment," reiterating the general views about parental decisionmaking outlined by the President's Commission. This statement addressed the unique constraints imposed by the Baby Doe rules but deferred discussion of decisions made for neonates to a later document, "The Initiation or Withdrawal of Treatment for High Risk Newborns," written by the Committee on the Fetus and Newborn. This distinction reflects the unique approach to decisionmaking necessitated in this population by the special nature of Baby Doe rules that only apply to infants under 1 year of age. The opening statement confirmed the AAP's position: "Medical treatment of infants should be based on what is in their best interest." But the document acknowledged that infants' best interests may be difficult to discern. The paper noted that the particular dilemma posed by this age group probably led to the schism between the rule utilitarian approach of the Baby Doe rules and guidelines supporting the best interests of the child. The paradox is that without support, many of the infants would die or suffer significant morbidity, but with support many would suffer catastrophic disabilities or a prolonged death. "The overall outcomes of either approach are disappointing."

Following the Baby Doe rules means that all except those imminently faced with death will be supported, thus assuring that no child who potentially could survive would die as the result of a decisionmaker's choice for no intervention. The cost of this utilitarian stand is that many infants could die slowly or suffer what many would feel to be unbearable disabilities to assure that no potential survivor dies because parental decisionmaking was allowed. Those supporting the best interests standard suggest that the family is best able to make choices for the infant, taking into account their family values and which set of risks is most appropriate for their child. The report emphasized the importance of communication with decisionmakers, supporting the concept of complete and accurate information as essential elements for good decisions, as suggested by the President's Commission.

The AAP policy was updated in 2007 after new members reviewed the previous recommendations. This new committee reaffirmed the best interests standard as the appropriate basis for neonatal decisions. The document reviewed the difficulty of providing an accurate prognosis for critically ill infants, and the policy supported the role of parents in decisionmaking. Further clarifying this position and paraphrasing the recommendations from the President's Commission in 1983, this policy statement supported foregoing intensive care in cases that are likely fatal or have a high risk for severe morbidity and always providing intensive care when the outcome is very likely to be survival with low risk for severe morbidity. The policy deferred to parental decisionmaking based on the best interests standard only in cases where "the prognosis is uncertain but likely to be very poor and survival may be associated with a diminished quality of life for the child." These standards should apply throughout the treatment of the infant with a recommendation for constant reappraisal of the infant's status.

Also in 2007, the AAP awarded the William G. Bartholome Award for Ethical Excellence to Loretta Kopelman, PhD, for her work in pediatric ethical issues. A vocal advocate of the best interests

standard throughout her career, she chose a defense of the best interests standard for neonatal care as the topic of her acceptance speech. Kopelman called on the AAP to withdraw its conflicted support of the Baby Doe rules in favor of fully supporting the best interests standard. Her argument included the observation that the official stance of the AAP—that the Baby Doe rules are compatible with the best interests standard—sprang from the misconception that the inclusion of reasonable medical judgment in the regulations can be interpreted as it was by the president of the AAP at the time the rules were promulgated. While the rules were in formulation, the AAP president stated: “It would appear that the final rule reaffirms the role of reasonable medical judgment and that decisions should be made in the best interests of infants.” This interpretation is clearly not the intent of the statement in the Baby Doe rules that allows the exercise of “reasonable medical judgment” only in the 3 explicit circumstances when lifesaving treatment is not required.

Kopelman reviewed the medical tradition of supporting the best interests standard, as well as the powerful arguments in support of this concept from bioethics panels appointed by Reagan and later by George W. Bush (both presidents advocated support of the Baby Doe rules). She argued that standing by the best interests standard for surrogate decisionmaking for everyone except children under the age of 1 year as specified in the Baby Doe rules is unwarranted. Kopelman said she could find no moral difference between the aged who may be unable to make their own decisions and newborn infants. If the best interests standard fulfills “three necessary and jointly sufficient conditions,” she noted, “the Best Interests Standard should be adopted as the only guidance principle for minors and incapacitated and incompetent adults without preferences or advance directives.”

Throughout the history of this conflict, there has been little examination of the extent to which society supports the Baby Doe rules. The ethics literature and the legal literature have most often argued against the rigidity of the Baby Doe rules as written. On the opposite side of the argument, attempts have been made, particularly during conservative administrations, to strengthen the regulatory applicability of the Baby Doe rules and generalize them from just those infants with handicaps to infants born at the threshold of viability.

Most recently, this goal has been supported by an interpretation that would apply the provisions of the Born Alive Infant Protection Act and the Emergency Medical Treatment and Labor Act (EMTALA) as means of more punitive enforcement. Dr Sadeth Sayeed summarized these efforts, reviewed the directives from various arms of HHS in 2005, and presented concerns that the normative ethical practices of decisionmaking following the best interests standard endorsed by the AAP were at risk by HHS's interpretation at that time. Specifically, Sayeed cited guidance documents interpreting the delivery room as a potential emergency department with the threat of legal action by federal agencies and by any individual who might be harmed under the EMTALA regulations. To date, no such allegations have been investigated, but the documents and directives survive.

During all these deliberations to decide how best to make decisions for infants, the overwhelming normative practice in neonatal medicine has been to follow the best interests standard, but the legality of this practice looms over the neonatal intensive care unit. However, in nearly 30 years of deliberations about the Baby Doe case and the legal activity prompted by the medical decisions made for that infant, only one case cites the Baby Doe rules.

In a letter to the editor of *Pediatrics*, Clark reviewed the case of *Montalvo v Borkovec*, in which a family brought action alleging that their very premature infant was resuscitated against their wishes.

They claimed that discussion of the prognosis was inadequate and that they did not consent to any treatment that would allow the physicians to proceed with resuscitation. The court ruled that under Wisconsin law informed consent was not necessary in this circumstance. The court supported this ruling by citing the Baby Doe regulations, with the opinion that withholding life-sustaining efforts was not a legal alternative because the child was not in a persistent vegetative state. Because the state of Wisconsin accepts federal funds for CAPTA, the Baby Doe regulations must be followed, the court noted. It is noteworthy that this case presents the only citation of the Baby Doe rules as legal precedent, before or since. Additionally, the case was not brought under the intended application of the Baby Doe rules as an action of child protective services. The Baby Doe rules were used to support a court decision that could stand on its own merits under Wisconsin law. Clark concluded that “discussion of Baby Doe was gratuitous and not necessary to the decision in the case.”

All of this history simply outlines the dilemma faced by those providing care for neonatal patients. It is clear that the Baby Doe rules and normative ethics do not concur regarding decisionmaking. Must one follow the law, which is very specific but has no history of enforcement and, by inference, is not the standard of care? The possibility that these rules would be legally problematic was foreshadowed by remarks early in the history of this debate. A review of the Baby Doe rulings in 1986 presented the controversy as it existed when the rules were formulated. The authors made the case that controversial laws created without widespread acceptance have an unpredictable course and “citizens will find other ways to preserve choices they think they ought to have.” Citing the likely unintended consequences of these rules, which include survival of infants with marginal health, Huefner concluded: “If the government demonstrates its genuine concern for the early and continuing stimulation of the infant’s development, perhaps a more integrated government role can emerge—one that will better balance the legitimate interests of the child, the parents, the medical community, and society.”

The predicted unintended results were borne out in a later review that cited many of the historically difficult positions brought about by concern that the Baby Doe rules might be enforced. This critique formulated three arguments opposing these rules. First, the rules address a problem that does not exist except in exceptional circumstances (a position frequently encountered in discussion of the Baby Doe rules). Second, a uniform federal standard oversimplifies the complex moral and ethical decisions presented by critically ill neonates. Third, the policy simply fails to follow intuition by excluding parents from any decision-making capacity in contrast to well-established legal tradition. The policy erroneously assumes that a decision in favor of life is always in the infant’s best interest, the critique noted, and this assumption conflicts with the normative ethic that quality of life contributes significantly to ethical decisionmaking. The article pointed out the general acceptance of quality of life as a factor: “The truth is that nearly all of us, the proponents of the federal policy included, hold such issues to be important in our daily lives.” After presenting the case against the Baby Doe rules, the authors called to eliminate the federal role in treatment decisions and to support decisionmaking by parents in consultation with the physicians caring for the child. The authors concluded that the approach “should not be swept aside with simplistic social policy that overlooks the profound ethical, medical, and legal questions that such situations pose.”

Where does all of this controversy leave those who daily make decisions for critically ill newborns? The AAP guidance is clear in its recommendation that the day-to-day decision-making process in almost all circumstances remains in the domain of the family and caretakers, with the normative practice to follow the best interests standard. The AAP acknowledges that the Baby Doe rules exist but maintains that the inclusion of “in the treating physician’s (or physicians’) reasonable medical

judgment” accommodates the normative practice. When law and practice conflict, actions in the courts usually provide guidance. The lack of legal case history to dispel the interpretation of the AAP might be viewed as tacit approval for this interpretation, but the possibility of enforcement continues to exist as long as the rules remain in place.

This long history of controversy begs for resolution, and when questions arise, the role of the hospital ethics committee is critical to the appropriate resolution. Few hospitals providing neonatal intensive care and fewer community hospitals have active infant ethics committees as proposed in the 1984 recommendations of the AAP. The Joint Commission on Accreditation of Healthcare Organizations (now known as The Joint Commission) mandates a process for addressing ethical concerns with wide latitude regarding the mechanism for meeting this requirement. Little evidence suggests that reviewing neonatal decisionmaking, as envisioned by the AAP and the President's Commission, is commonly considered part of this process. Furthermore, no evidence demonstrates that a standard of care or consensus exists for the ongoing review of decisions made to forego life-sustaining treatment for neonates in any forum.

How then should we proceed to ensure that appropriate decisions are made for these vulnerable patients? We might ask, despite all the controversy in the literature, if the problem really exists. Although a great deal of literature discusses the disparate viewpoints of the Baby Doe rules and the best interests alternative, cases questioning the decisions made are quite rare. This fact is supported by the dearth of legal cases citing the Baby Doe regulations; also, no state has lost federal funds for failure to comply with CAPTA. Infant ethics committees are not readily apparent, and no literature documents regular review of decisions to withhold life-sustaining treatment.

It seems that the best approach is to be prepared to address concerns as they arise. When questions are posed concerning the management of a newborn infant, the questions should be addressed through the process mandated by The Joint Commission. In most instances, this process entails a hospital ethics committee. It is incumbent on those serving in this advisory capacity to understand both the history and the controversy surrounding neonatal decisions for life-sustaining treatments. Any recommendations must consider the specific requirements of the Baby Doe regulations and, according to what appears to be the de facto standard of care, the requirements for the best interests standard. This process should begin by considering the goals of infant ethics committee reviews suggested by the President's Commission in 1983:

First, verify that the best information available is being used.

Second, confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate.

Third, resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute.

Finally, refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate.

This process, if carried out with consideration of the suggested goals, should ensure that the best possible decisions are made for newborn infants. Recognizing that these circumstances are difficult for all parties involved, the President's Commission believes that this process “has the potential

both to guarantee a discussion of the issues with a concerned and disinterested 'representative of the public' and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.”

This statement has proven prescient in light of the very public controversy surrounding the death of Terri Schiavo. The potential to propagate controversy via television, internet, Twitter, and personal blogs was demonstrated in the hijacking of what should have been very private deliberations to serve as a platform for the political and private interests of many others beyond the patient and her family. I was involved, remotely and quietly, in that case, but gave advice that was not in line with the advice or positions taken by either side in the case, but which I believed to be correct in light of the law and facts that were proven as opposed to speculation. As in many cases, bad or muddled facts give rise to bad law or legal decisions. In light of the controversy surrounding decisions at the beginning of life, the potential for such trials by media always looms over what should be, as much as possible, private decisions. I can only hope that careful, knowledgeable consideration, following the tenets of the best interests standard when such cases present themselves, will result in gentle resolution of the concerns in a private way. I realize that some cases will, often because of complexity, have to be resolved more formally. But preferably without the controversy.

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CAPACITY, COMPETENCY, GUARDIANSHIP, CONSERVATORSHIP, AND OTHER CANS OF WORMS

1. WHAT IS COMPETENCY?

In forensic terms, competency generally refers to decision-making and communicating capacity. Widely accepted definition – the capacity to: understand information relevant to the issue at hand; think rationally about alternative courses of action; appreciate one’s situation as a person confronted with a specific decision; and, express a choice among alternatives. Statutes often include the term “capacity to know and understand or ability to know and understand” followed by a list. Problem is that the determination is often retroactive, without much clear documentation, so the expert must infer, from evidence of the person’s general intellectual function, what the person knew and understood. This can also be a problem in contemporaneous examinations where an unskilled examiner, emotional arousal and such can lead to atypical performance that does not accurately reflect the actual capacity.

2. TYPES OF CIVIL COMPETENCY COMMON TO ELDERLAW PRACTICE

a. Competency to enter into a contract or make a gift - technically “contractual and donative capacity”. Despite the difference in “future orientation” of contracts and “present orientation” of gifts, legal standards usually do not vary between the two. Typically arises when someone (the original giver of the gift or signer of the contract, or someone affected thereby) wants to escape responsibility for the contract or gift – not have to perform the contract or wants to retrieve the assets gifted. Also, is the common question in most conservatorships - can the proposed ward manage his or her own finances or resist fraud or undue influence?

Generally, many states, but not Idaho, hold that the appointment of a conservator creates an irrebuttable or rebuttable presumption that the conservatee lacks contractual and donative capacity, but may allow marriage (e.g. California). The California statute, for example, says, “A rebuttable presumption affecting the burden of proof that a person is of unsound mind shall exist if the person is substantially unable to manage his or her own financial resources or resist fraud or undue influence.” Contractual competency is usually through to be “higher” level of capacity, requiring more intact intellectual function, than testamentary capacity. One court referred to testamentary capacity as “the weakest class of sound minds” – humorous, since most Wills start out “Being of sound mind”. The Restatement Second of Contracts provides, “A person incurs only voidable contractual duties by entering into a transaction if by reason of mental illness or defect (a) he is unable to understand in a reasonable manner the nature and consequences of the transaction, or (b) he is unable to act in a reasonable manner in relation to the transaction and the other party has reason to know of his condition.” This adds a reasonable action requirement in addition to the intellectual requirement of “understanding” and therefore is a higher standard than testamentary capacity.

b. Competency to make a Will Most states define testamentary capacity as having the ability to understand the nature of the testamentary act, understand and recollect the nature and situation of his or her property, and remember and understand his or her relations to his or her living descendants, spouse, and parents, and those whose interest are affected by the will, or some portion of those. Some states add that the testator must be free of “delusions or hallucinations” that affect or direct the devising of the property in the Will. Idaho law gets really complicated here (hah!), providing in Idaho Code §15-2-501: “Who may make a will. — Any emancipated minor or person eighteen (18) or more years of age who is of sound mind may make a will. A married woman may dispose of her property, whether separate or community, in the same manner as any other person subject to the restrictions imposed by this code.” Real helpful.

In general, if lack of testamentary capacity is shown the entire Will or codicil is invalid. There is usually a general presumption of competency, and if a person has occasional periods of lucidity, it is presumed that the Will was done during such a period. The trend in more recent cases is that illnesses such as Alzheimer's and vascular dementia are progressive, so it is unlikely that testamentary capacity would return once lost, even for brief periods. Usually there is not any contemporaneous examination of the testator, nor any documented evaluations in the time period of the Will, so it is very difficult to prove, retrospectively, that a testator lacked testamentary capacity at the precise moment when the Will was executed.

c. Competency to execute a trust Trusts are increasingly popular. But, trusts are often more complicated than Wills, with more detailed provisions, are more abstract in theory than wills. Additionally, trusts are, in effect, contracts, and often require the transfer of property to the trust, which would seem to require the "contractual and donative capacity" tests to be used. Almost all trustees are empowered to enter into contracts involving the trust assets, so the creator of the trust should have contractual capacity to so authorize the trustee, since there is a legal maxim that one should not be able to endow a capacity one does not possess. California, for example, is currently looking at requiring contractual capacity to create and trust, but testamentary capacity for amendments to a trust that affect only post-death dispositions from the trust. The proposed Uniform Trust Act, which has been enacted in about 20 States (but with substantial modifications in each State), and which has not been adopted in Idaho (we did a 2.5 year review of the Act), provides that the ability to make a trust is a testamentary capacity.

d. Competency to care for oneself and manage one's finances All 50 states have laws for appointment of guardians and/or conservators, with various names, for persons incompetent to care for themselves or manage their own property. In Idaho, and most states, "guardian" means caring for the individual and "conservator" means caring for the property. In many States, such as California, these are called "guardian of the person" and "guardian of the estate". In Idaho, we have made substantial revisions to the old law, which had the Uniform Probate Code definition of "impaired by reason of mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, or other cause", and we now have the following language:

15-5-101 Definitions and use of terms * * * "Incapacitated person" means any person who is impaired, except by minority, to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person, provided, that the term shall not refer to a developmentally disabled person as defined in section 66-402(5), Idaho Code, and provided further that:

(1) "Incapacity" means a legal, not a medical disability and shall be measured by function limitations and it shall be construed to mean or refer to any person who has suffered, is suffering, or is likely to suffer, substantial harm due to an inability to provide for his personal needs for food, clothing, shelter, health care, or safety, or an inability to manage his or her property or financial affairs;

(2) Inability to provide for personal needs or to manage property shall be evidenced by acts or occurrences, or statements which strongly indicate imminent acts or occurrences; material evidence of inability must have occurred within twelve (12) months prior to the filing of the petition for guardianship or conservatorship;

(3) Isolated instances of simple negligence or improvidence, lack of resources, or any act, occurrence, or statement, if that act, occurrence, or statement is the product of an informed judgment, shall not constitute evidence of inability to provide for personal needs or to manage property;

(4) "Informed judgment" means a choice made by a person who has the ability to make such a choice, and who makes it voluntarily after all relevant information necessary to making the decision has been provided, and who understands that he is free to choose or refuse any alternative available and who clearly indicates or expresses the outcome of his choice.

So Idaho has a sophisticated definition, rather than the somewhat simplistic definitions of the past. These criteria refer to complex social behaviors rather than to cognitive decisional impairments that presumably underlie the functional deficits. We have also, correspondingly, greatly expanded the required report of the court visitor to reflect not only these criteria, but also the wishes of the ward, if ascertainable.

e. What is undue influence? Usually this claim is made in combination with lack of capacity, whether to make a contract, will, trust, or gift. In California, substantial inability to resist fraud or undue influence is listed as one of the criteria for appointment of a conservator. This may arise in the context of financial exploitation cases as well. But, undue influence is a complex and poorly defined legal concept. Often a “will substitution test” is used – was the person’s mind so controlled by another person that what appears to be his or her will is actually the will of another person. May or may not require coercion, compulsion, or restraint. In the contract field, may be (1) use, by one in whom confidence is reposed by another, or who holds real or apparent authority over the person, of such influence or authority for obtaining an unfair advantage; or, (2) taking an unfair advantage of another’s “weakness of mind”; or, (3) taking a grossly oppressive and unfair advantage of another’s “necessities or distress”.

There may be two legal theories of undue influence – the “susceptibility” model and the “presumption” model. The susceptibility model emphasizes the mental weakness of the victim, while the presumption model emphasizes the relationship between the victim and the receiver of the advantage. Both say that even minimum mental impairment is sufficient. In presumption models, just the fact of a particular relationship (e.g. attorney, priest, trusted advisor, boss, etc.) may be enough to shift the burden of proof. Idaho statutes have been changed to create a presumption of undue influence in certain relational situations - bequests to an institution in which the decedent resided less than one year, or to employees working at the residence of the decedent. The language regarding an employee at the home has to be carefully read, since it is not limited to employees of nursing homes, etc., but applies to any person employed at the home. For example, a person mowing the lawn could conceivably be covered. The one year provision must likewise be carefully read as it applies to employees at the home (essentially, the decedent must have been out of the home for more than one year before the presumption of undue influence ceases).

15-2-616. RESTRICTIONS ON DEVISES TO NURSING HOME OR RESIDENTIAL OR ASSISTED LIVING FACILITY OPERATORS. A devise or bequest involving either real or personal property, directly or indirectly, to any person who owns, operates or is employed at a nursing home, residential or assisted living facility or any home, including the testator’s home, whether or not licensed, in which the testator was a resident within one (1) year of his death shall be presumed to have been the result of undue influence, rebuttable by clear and convincing evidence. This section shall apply to all property passing by testate succession after July 1, 1983, regardless of when the will was written; provided, this section shall in no way limit or affect the rights of a beneficiary who is related to the testator, or who is a charitable or benevolent society or corporation; provided further that the foregoing limitations shall not apply to wills of persons whose death is caused by accidental means and whose wills are executed prior to the accident which results in death.

3. EXPLOITING THE ELDERLY AND COMPETENCY The foregoing tests may give retroactive protection to the elderly from exploitation if they are impaired in some manner. But, my experience has been that lack of capacity or undue influence is very difficult to prove, especially since many of the facts are hidden. For example, in a case I just finished up, an elderly single widower with Alzheimer’s dementia is involved with a younger person who has, mostly voluntarily, taken over the care-giving for the elderly person, but is being paid, rather substantially. The widower was cognitively impaired, but not to the extent that it was obvious in casual social interactions. The impairment was in “Frontal executive function”, and those who best knew the widower thought his judgment was not what it used to be. Not in this case, but in many cases, there may be romantic involvement between the younger and elder person. The younger person isolated the widower, created a “siege mentality”, created dependence, made the widower feel powerless without the younger person, used fear and deception, and kept the widower unaware of all these tactics. The widower ended up giving substantial assets to the perpetrator, named him as POA and Health Care agent, named him as sole taker in the widower’s will. Since the widower was totally isolated from his family (the perpetrator had convinced the widower that the family was trying to institutionalize the individual, was out to get his money, and thought the widower was “crazy”), this had progressed

to emergency status by the time I was involved. We got back all the assets and removed the person from the home. Often, the result is not that good. Last session, two statutory changes were made to add abuse of a financial power of attorney to the Vulnerable Adult Exploitation statute and the Consumer Protection Act, thereby creating clear civil and criminal coverage. As monitoring of conservatorships has increased in both frequency and thoroughness, more abuse has occurred through powers of attorney.

4. USE OF EXPERTS Use of an expert is indicated if there are signs of mental impairment as follows:

- a. deficits in attention, concentration, and recent memory, with difficulty in following the thread of a conversation, with repeating of questions and statements and vague or contradictory answers to questions;
- b. events being described out of temporal sequence, inaccurate dates, times, places, or other incorrect descriptions of past events;
- c. speech that has little content, circumlocutions, inability to come up with words, and inappropriate responses to questions;
- d. poor judgment, impulsivity, inability to think abstractly, and inability to plan and carry out actions with multiple steps.

The elder law attorney is often the first level of reviewing decisional competence. The standards of practice for attorneys give little guidance on the assessment of such situations, or what to do. So, the attorney should seek help from an appropriate diagnostician, acting in effect as de facto guardian.

Methods of capacity assessments - an incomplete listing:

- a. Mini-Mental State Examination (MMSE);
- b. Understanding of Treatment Disclosure and Thinking Rationally About Treatment Measures;
- c. Edelstein's Hopemont Capacity Assessment Inventory;
- d. Neurobehavioral Cognitive Status Examination;
- e. Dementia Rating Scale;
- f. Wechsler Memory Scale – Revised Logical Memory Test;
- g. Geriatric Depression Scale;
- h. Center For Epidemiological Studies Depression Scale;
- i. Short Psychiatric Evaluation Schedule;
- j. Global Deterioration Scale;
- k. Alzheimer's Disease Assessment Scale;
- l. Brief Cognitive Rating Score;
- m. Cambridge Mental Disorders of the Elderly Examination;
- n. Dementia of the Alzheimer Type Inventory;
- o. Dementia Diagnostic Screening Questionnaire;
- p. Mental Status Questionnaire; and,
- q. Executive Cognitive Function (ECF) Measure.

Usually, the attorney wants a definitive, unambiguous, clear answer to the question of decisional capacity. The above tests are attempts to have easily administered measure that always produces a clear, objective, numerical readout with understandable appeal to attorneys and judges. None of the foregoing meet that magical test. There are logical limitations in such testing, which I will not go into here, that make this magical test ultimately impossible. Just differences in education, culture, language, ethnicity, and such will skew results. Generally, about all that the attorney can expect from the professional, realistically, is:

- a. the person's orientation to person, place, time, and situation;
- b. recent and remote memory and logical sequencing;
- c. intellectual capacity - ability to understand abstract ideas and make reasoned judgments based on that ability;
- d. mood and affect;
- e. content of thought and perception, especially as to delusions, illusions, and hallucinations;

- f. visible behavior, especially of agitation and anxiety; and,
- g. psychiatric disturbances that might affect judgment.

It is then the job of the legal system to apply these to a particular case and particular decisional capacity question.

5. GUARDIANSHIP

Guardianship of adults in Idaho falls under Idaho Code §§15-5-301 et seq. The major provisions of this Chapter are:

- a. Testamentary appointment Under 15-5-301, a guardian can be appointed by Will, although this is rare for adults. Usually this will be the appointment by one spouse of a guardian of the other, incapacitated, spouse. The nominated guardian simply files an acceptance with the probating court. We will be doing some major expansion of this language in this year's legislature.
- b. Venue §15-5-302 - where the protected person resides or is present, or where the committing court sits if committed.
- c. Procedure The Petition can be by: (1) the incapacitated person; or, (2) any person interested in the welfare of the incapacitated person. The statute is clear that the least restrictive form of guardianship should be sought and granted, "by establishing a guardianship that permits incapacitated persons to participate as fully as possible in all decisions affecting them; that assists such persons in meeting the essential requirements for their physical health and safety, in protecting their rights, in managing their financial resources, and in developing or regaining their abilities to the maximum extent possible; and that accomplishes these objectives through providing, in each case, the form of guardianship that least interferes with legal capacity of a person to act in his own behalf".

When the petition is filed, the Court sets a date for hearing and appoints a guardian ad litem and a court visitor and the court physician, all of whom report to the Court, in writing or at hearing. In a minor guardianship, only a GAL, or an attorney for the minor if of sufficient maturity, may be appointed, and the Court can refuse to make any appointment. The Court can appoint additional experts, including a mental health professional (psychiatrist, psychologist, gerontologist, licensed social worker, or licensed counselor). The Court visitor examines and interviews the protected person and all other appropriate persons. The proposed guardian has to attend the hearing, at which evidence can be presented, witnesses and documents subpoenaed. The protected may, but often does not, attend. The hearing can be closed upon request. We are seeking substantial expansion of the ability to close hearings, seal records, and redact information, through amendments to Rule 32 and some statutory language. Notice has to be given to all appropriate persons and entities of the hearing.

At or after the hearing, the Court, if appropriate, enters the Order of appointment and issues Letters of Guardianship. The test is if "the person for whom a guardian is sought is incapacitated and ... the appointment is necessary or desirable as a means of providing continuing care and supervision of the person of the incapacitated person." Then, or later, the powers of the guardian can be limited. The guardian accepts in writing. The guardianship is terminated by the death of the guardian or ward, the incapacity of the guardian, removal or resignation of the guardian, or the gaining of full competency by the ward.

- d. Role of Visitor The visitor is a protection for the alleged incapacitated person. The visitor "a person who is trained in law, nursing, psychology, social work, or counseling or has other qualifications that make him suitable to perform the function and is an officer, employee or special appointee of the court with no personal interest in the proceedings. The report is detailed in §15-5-308, which goes into considerable detail: (1) nature, cause and degree of incapacity; (2) needs of the person for care and treatment; (3) evaluation of appropriateness of guardian and steps to be taken by the guardian; (4) abilities of the person and recommendation of full or limited powers to the guardian, and, if limited, specifics of powers; (5)

expressions by the incapacitated person about the proposed guardian; (6) financial analysis; (7) persons with significant interest in the welfare of the person; (8) qualifications and relationship of the proposed guardian; (8) how the person responded to being advised of the proceedings and the right to be present at hearing; and, (9) recommendations on bond requirements.

e. Temporary Guardians §15-5-310. This has been made more difficult to get, on purpose, because of past abuses. Temporary guardianship can be granted only if: (1) an existing guardian is not properly performing; or, (2) an emergency exists such that the likely result will be substantial harm to the alleged incapacitated person's health, safety, or welfare, and there is no other person acting. The appointment can be for a maximum of 60 days and is limited to the powers absolutely necessary, or the least restrictive. A guardian ad litem is appointed, and the incapacitated person also has the right to substitute an attorney for the guardian ad litem. If the appointment is made without notice to the incapacitated person because of emergency, notice must be given within 48 hours and a hearing held within 5 days, if requested, where a visitor and physician are appointed.

f. Priority §15-5-311. The priority list for guardians: (1) the person preferred by the incapacitated person unless good cause to the contrary is shown, including as indicated by prior naming under a durable power of attorney for health care; (2) spouse; (3) adult child; (4) parent; (5) any relative where the incapacitated person resided for more than 6 months; or, (6) a person nominated by the person caring for, or paying benefits to, the incapacitated person.

g. Powers and Duties of Guardian §15-5-312. The guardian has the "powers and responsibilities of a parent who has not been deprived of custody of his unemancipated minor child except that a guardian is not legally obligated to provide from his own funds for the ward and is not liable to third persons for acts of the ward". A specific list follows: (1) custody of the person; (2) provisions for care, comfort, and maintenance, training, education, and care of property; (3) consents or approvals for medical or other professional care, counsel, treatment, or service; (4) if no conservator is appointed, a number of financial powers; (5) duty to report by guardian, at least once per year, with copies to all interested parties; (6) duty to turn over excess assets to a conservator. The guardian can be compensated for acting, including room and board and can delegate powers.

6. CONSERVATORSHIP Conservatorship is Idaho Code §§15-5-401 et seq. Much of the treatment overlaps with guardianships, especially in the visitor area. Some highlights:

a. Procedure Much like the guardianship. Requires that the Court, as to a minor, "determines that a minor owns money or property that requires management or protection which cannot otherwise be provided, has or may have business affairs which may be jeopardized or prevented by his minority, or that funds are needed for his support and education and that protection is necessary or desirable to obtain or provide funds" or, as to an adult "determines that (1) the person is unable to manage his property and affairs effectively for reasons such as mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, confinement, detention by a foreign power, or disappearance; and (2) the person has property which will be wasted or dissipated unless property management is provided, or that funds are needed for the support, care and welfare of the person or those entitled to be supported by him and that protection is necessary or desirable to obtain or provide funds." Notice must be given to appropriate persons. As in guardianship, the least restrictive and intrusive method of appointment should be used.

b. Powers and Duties of Conservator §15-5-408 has a long list of the powers and duties of the conservator, including such powers as making gifts, contracts, creation of trusts and so forth, in addition to the standard and necessary powers to pay bills and so forth set forth in §15-5-417. The Court can order protective arrangements or authorize single transactions. There are also special provisions for minor's compromises. Accounts must be filed at least annually, along with an initial inventory within 90 days. Termination is much like guardianship.

c. Penalties The Court, by recent amendment, has the ability to impose fines and make charging orders and judgments against a conservator or guardian if the conservator or guardian: (1) makes a substantial misstatement on filings; or, (2) is guilty of gross impropriety in handling the ward's property; or, (3) willfully fails to file the required reports, but only after written notice and a grace period of two months. Additionally, the conservator is individually liable for any misdeeds and mistakes.

d. Miscellaneous The appointment of a conservator vests title to all property of the ward in the conservator. The conservator can record the Letters of Conservatorship to give notice of the appointment and thereof of the vesting of title. Also, persons dealing with a conservator in good faith are immune from liability.

e. Distributive Powers In §15-5-425, and in surrounding sections, there is a long list of the principles under which the conservator is to distribute property, both during the lifetime of the ward and at the ward's death or obtaining the age of majority. The principles are broad and cover a wide variety of options in a flexible manner.

f. Minors after age 18 By recent amendment, the conservatorship can be extended from age 18 to age 21. This must be presented to the court before the minor reaches 18, not after. The minor, after reaching age 18, can petition to terminate the extended conservatorship, but must show proof of ability to manage the minor's financial affairs, with appropriate evidence, a list of which is in §15-5-433.

g. Preservation of Estate Plan The conservator is to carry out and preserve the estate plan of the ward as it exists at the appointment. This can get very tricky if the ward has a detailed estate plan leaving certain specific assets (real estate for example) to certain heirs, but is incurring large monthly expenses for care, and especially if the general heirs are different from the specific heirs on the property.

7. SOME PRACTICAL PROBLEMS

a. While a conservator is to protect and preserve the estate plan of the protected person, a series of problems can arise:

i. What is the estate plan? There may be multiple documents, or the documents may not have been found. What about documents made with questionable capacity? As noted above, a person may need a conservatorship, but still be able to make a Will and perhaps a trust, so the estate plan may change after the appointment of a conservator.

ii. What if the needs of the protected person require using estate assets? Generally, specific bequests are to be protected in preference to a residuary bequest, which may not be what the protected person intended. What if a specific bequest is of an asset that is impractical to keep (a house, boat, expensive jewelry, etc.)? What about survivorship designations such as TOD, POD, JRWROS, ect.?

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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

1 (eye slanting upward, small ears, small mouth, small nose with flattened nasal bridge, short neck,
2 small hands and feet, short stature, and low muscle tone), and often heart defects (about half),
3 vision (60%), hearing loss (75%) and other health problems. Tend to develop Alzheimer's earlier
4 and more often than general public (about 25% over age 35 have symptoms). Severity varies
5 widely. About 1 in 700 babies each year in US. Currently more than 400,000 in US.

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

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

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

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

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

24 There a lot more, but relatively rare.

25 c. Causes

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

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

39 d. Diagnosis and quantification

40 Developmental disabilities can be initially suspected when a child does not reach expected child

1 development stages. Subsequently, a differential diagnosis may be used to diagnose an underlying
2 disease, which may include a physical examination and genetic tests. The degree of disability can be
3 quantified by assigning a developmental age to a person, which is age of the group into which test scores
4 place the person. This, in turn, can be used to calculate a developmental quotient (DQ): $DQ =$
5 $\frac{\text{Developmental age}}{\text{Chronological age}} * 100$.

6 e. Associated issues

7 i. Physical health issues

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

17 ii. Mental health issues (dual diagnoses)

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

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

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

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

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

1 f. Abuse and vulnerability

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

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

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

27 g. Challenging behavior

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

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

1 developmental disabilities can often associated with specific mental health problems.

2 Experience and research suggests that what professionals call “challenging behavior” is often a reaction
3 to the challenging environments that those providing services create around people with developmental
4 disabilities. “Challenging behavior” in this context is a method of communicating dissatisfaction with the
5 failure of those providing services to focus on what kind of life makes most sense to the person, and is
6 often the only recourse a developmentally disabled person has against unsatisfactory services or treatment
7 and the lack of opportunities made available to the person. This is especially the case where the services
8 deliver lifestyles and ways of working that are centered on what suits the service provider and its staff,
9 rather than what best suits the person.

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

14 h. Societal attitudes

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

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

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

42 Ignoring the prevailing attitude, Civitans adopted service to the developmentally disabled as a major
43 organizational emphasis in 1952. Their earliest efforts included workshops for special education teachers
44 and day camps for disabled children, all at a time when such training and programs were almost

1 nonexistent. In the United States, the segregation of people with developmental disabilities wasn't widely
2 questioned by academics or policy-makers until the 1969 publication of Wolf Wolfensberger's seminal work
3 "The Origin and Nature of Our Institutional Models", drawing on some of the ideas proposed by S.G. Howe
4 100 years earlier. This book posited that society characterizes people with disabilities as deviant,
5 sub-human, and burdens of charity, resulting in the adoption of that "deviant" role. Wolfensberger argued
6 that this dehumanization, and the segregated institutions that result from it, ignored the potential productive
7 contributions that all people can make to society. He pushed for a shift in policy and practice that
8 recognized the human needs of "retardates" and provided the same basic human rights as for the rest of
9 the population.

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

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

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

28 i. Services and support

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

40 j. Education and training

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

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

9 k. At-home and community support

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

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

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

28 l. Residential accommodation

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

39 m. Employment support

40 Employment support usually consists of two types of support:

41 Support to access or participate in integrated employment, in a workplace in the general
42 community. This may include specific programs to increase the skills needed for successful

1 employment (work preparation), one-to-one or small group support for on-the-job training, or
2 one-to-one or small group support after a transition period (such as advocacy when dealing with
3 an employer or a bullying colleague, or assistance to complete an application for a promotion).

4 The provision of specific employment opportunities within segregated business services. Although
5 these are designed as "transitional" services (teaching work skills needed to move into integrated
6 employment), many people remain in such services for the duration of their working life. The types
7 of work performed in business services include mailing and packaging services, cleaning,
8 gardening and landscaping, timber work, metal fabrication, farming and sewing.

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

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

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

27 n. Day services

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

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

37 o. Advocacy

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

1 needs.

2 p. Other types of support

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

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

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

21 **2. IDAHO STATUTES**

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

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

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

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

39 Fifth, the Uniform Laws Commission has been working on a complete revision of the Uniform Probate
40 Code as if applies to conservatorship/guardianship. I am an Observer on that committee and have made
41 a number of suggestions for changes or additions in language.. The final draft, subject to style review, was

1 adopted in July of 2017. Official Comments will be issued in October of 2017. Review of that draft
2 legislation in Idaho will take, in my experience, about 2 or more years.

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

5 The original approach of the State of Idaho, consistent with the factors discussed above, can be seen by
6 the outline of Title 66 State Charitable Institutions, which contains Treatment and Care of the
7 Developmentally Disabled as Chapter 4, especially the earlier chapters 1-8, which are the older law.

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

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

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

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

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

40 (5) "Developmental disability" means a chronic disability of a person which appears before the age
41 of twenty-two (22) years of age and:
42 (a) Is attributable to an impairment, such as intellectual disability, cerebral palsy, epilepsy,

1 autism or other condition found to be closely related to or similar to one (1) of these
2 impairments that requires similar treatment or services, or is attributable to dyslexia
3 resulting from such impairments; and
4 (b) Results in substantial functional limitations in three (3) or more of the following areas of
5 major life activity: self-care, receptive and expressive language, learning, mobility,
6 self-direction, capacity for independent living, or economic self-sufficiency; and
7 (c) Reflects the need for a combination and sequence of special, interdisciplinary or generic
8 care, treatment or other services which are of lifelong or extended duration and individually
9 planned and coordinated.

10 Further in that section:

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

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

- 16 (a) A substantial risk that physical harm will be inflicted by the respondent upon his own
17 person as evidenced by threats or attempts to commit suicide or inflict physical harm on
18 himself; or
- 19 (b) A substantial risk that physical harm will be inflicted by the respondent upon another as
20 evidenced by behavior which has caused such harm or which places another person or
21 persons in reasonable fear of sustaining such harm; or
- 22 (c) That the respondent is unable to meet essential requirements for physical health or
23 safety.

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

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

29 Venue for court proceedings is straightforward:

30 66-403. COURT JURISDICTION. Judicial proceedings authorized by the provisions of this chapter
31 shall be had in the district court of the county where the respondent resides or is found.

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

34 66-404. PROCEEDINGS FOR APPOINTMENT OF GUARDIANS AND CONSERVATORS. (1) A
35 person with a developmental disability or any person interested in his welfare may petition for a
36 finding of legal disability or partial legal disability and appointment of a guardian and/or conservator.

37 (2) The petition shall:

- 38 (a) State the names and addresses of the persons entitled to notice under subsection (4)
39 of this section;
- 40 (b) Describe the impairments showing the respondent is developmentally disabled, the
41 respondent's ability to receive, evaluate and communicate information, and the
42 respondent's ability to manage financial resources and meet essential requirements for

1 physical health or safety;

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

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

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

7 (3) Upon filing of a petition, the court shall set a date for a hearing, appoint an attorney to represent
8 the respondent in the proceedings unless the respondent has an attorney, and authorize an
9 evaluation committee to examine the respondent, interview the proposed guardians and/or
10 conservators and report to the court in writing. The report shall contain:

11 (a) A description of the nature and extent of the evaluation and the alleged impairments,
12 if any;

13 (b) A description of the respondent's mental, emotional and physical condition; educational
14 status; and adaptive and social skills;

15 (c) A description of the services, if any, needed by the respondent to meet essential
16 requirements for physical health and safety, and/or manage financial resources;

17 (d) A recommendation regarding the type and extent of guardianship or conservatorship
18 assistance, if any, required by the respondent and why no less restrictive alternative would
19 be appropriate;

20 (e) An opinion regarding the probability that the extent of the respondent's disabilities may
21 significantly lessen, and the type of services or treatment which may facilitate improvement
22 in the respondent's behavior, condition, or skills;

23 (f) The respondent's preference, if any, regarding the person or persons to be appointed
24 as guardian and/or conservator;

25 (g) The suitability of the person or persons proposed as guardian and/or conservator; and

26 (h) The signature of each member of the evaluation committee with a statement of
27 concurrence or nonconcurrence with the findings and any dissenting opinions or other
28 comments of the members.

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

31 (a) The respondent;

32 (b) The respondent's spouse, parents and adult children, or if none, the respondent's
33 closest relative, if any can be found; and

34 (c) Any person who is currently serving as guardian, conservator or who is providing care
35 for the respondent.

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

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

41 (6) At the hearing the court shall:

42 (a) Determine whether the respondent has a developmental disability;

43 (b) Evaluate the respondent's ability to meet essential requirements for physical health or
44 safety and manage financial resources;

45 (c) Evaluate the ability of the proposed guardian and/or conservator to act in the
46 respondent's best interests to manage the respondent's financial resources and meet
47 essential requirements for the respondent's physical health or safety;

48 (d) Determine the nature and scope of guardianship or conservatorship services necessary
49 to protect and promote the respondent's well-being; and

50 (e) Evaluate the ability of the respondent or those legally responsible to pay the costs
51 associated with the judicial proceedings and fix responsibility therefor.

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

3 (a) The proposed guardian or conservator has submitted to and paid for a criminal history
4 and background check conducted pursuant to section 56-1004A(2) and (3), Idaho Code;

5 (b) In the case of a petition for guardianship and pursuant to an order of the court so
6 requiring, any individual who resides in the incapacitated person's proposed residence has
7 submitted, at the proposed guardian's expense, to a criminal history and background check
8 conducted pursuant to section 56-1004A(2) and (3), Idaho Code;

9 (c) The findings of such criminal history and background checks have been made available
10 to the evaluation committee by the department of health and welfare; and

11 (d) The proposed guardian or conservator provided a report of his or her civil judgments
12 and bankruptcies to the evaluation committee and all others entitled to notice of the
13 guardianship or conservatorship proceeding pursuant to subsection (4) of this section.

14 (8) The provisions of paragraphs (a) and (d) of subsection (7) of this section shall not apply to an
15 institution nor to a legal or commercial entity.

16 (9) Each proposed guardian and conservator and each appointed guardian and conservator shall
17 immediately report any change in his or her criminal history and any material change in the
18 information required by subsection (7) of this section to the evaluation committee, all others entitled
19 to notice of the guardianship or conservatorship proceeding pursuant to subsection (4) of this
20 section and to the court.

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

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

24 Second, there is not an appointment of a Guardian ad Litem attorney. Instead, there is the
25 appointment of an attorney by the Court unless the person has their own attorney. Despite that, I
26 have routinely been appointed as a Guardian ad Litem in DD cases. I have written articles and
27 done seminars on the differences, especially ethically, between an attorney for a person in
28 guardianship and a Guardian ad Litem. And some statutes refer to "an attorney with the powers
29 of a Guardian ad Litem", which really muddies the waters.

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

33 §66-405 is extremely important to understand in treating developmentally disabled individuals. It is crucial
34 to understand this section and especially what it does not cover. This section contains what are commonly
35 called the "Baby Doe Regs". The accompanying Addendum has an extensive history of the Baby Doe Regs
36 and also an extensive discussion of their effect in the neonatal area primarily. However, it is very relevant
37 to DD law, and to treatment generally, because much of the terminology and principles resulting from the
38 Baby Doe case and Regs has ended up in Idaho's DD act and in the Idaho Medical Consent and Natural
39 Death Act.

40 66-405. ORDER IN PROTECTIVE PROCEEDINGS. (1) If it is determined that the respondent
41 does not have a developmental disability but appears in need of protective services, the court may
42 cause the proceeding to be expanded or altered for consideration under the uniform probate code.

43 (2) If it is determined that the respondent is able to manage financial resources and meet essential
44 requirements for physical health or safety, the court shall dismiss the petition.

45 (3) If it is determined that the respondent has a developmental disability and is unable to manage

1 some financial resources or meet some essential requirements for physical health or safety, the
2 court may appoint a partial guardian and/or partial conservator on behalf of the respondent. An
3 order establishing partial guardianship or partial conservatorship shall define the powers and duties
4 of the partial guardian or partial conservator so as to permit the respondent to meet essential
5 requirements for physical health or safety and to manage financial resources commensurate with
6 his ability to do so, and shall specify all legal restrictions to which he is subject. A person for whom
7 a partial guardianship or partial conservatorship has been appointed under this chapter retains all
8 legal and civil rights except those which have by court order been limited or which have been
9 specifically granted to the partial guardian or partial conservator by the court.

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

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

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

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

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

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

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

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

6 If adult protective services or the protection and advocacy system determines that withholding of
7 medical treatment violates the provisions of this section, they may petition the court for an ex parte
8 order to provide or continue the medical treatment in question. If the court finds, based on affidavits
9 or other evidence, that there is probable cause to believe that the withholding of medical treatment
10 in a particular case violates the provisions of this section, and that the life or health of the patient
11 is endangered thereby, the court shall issue an ex parte order to continue or to provide the
12 treatment until such time as the court can hear evidence from the parties involved. Petitions for
13 court orders under this section shall be expedited by the courts and heard as soon as possible. No
14 bond shall be required of a petitioner under this section.

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

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

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

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

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

25 66-409. AUTHORITY TO ADMIT DEVELOPMENTALLY DISABLED PERSONS. The head of any
26 facility licensed under state law is authorized to admit for observation, diagnosis, care or treatment
27 any developmentally disabled person for services provided by that facility.

28 66-412. RIGHTS IN FACILITIES. (1) Every developmentally disabled person admitted to any
29 facility shall be entitled to humane care and treatment.

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

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

36 (a) To be free from mental and physical abuse including that which arises from acts of
37 negligence;

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

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

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

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

- (f) To have free access to established procedures to voice grievances and to recommend changes in the policies and/or services being offered at the facility;
- (g) To practice his religion;
- (h) To be informed of his medical and habilitative condition, of services available in the facility and the charges therefor;
- (i) To have reasonable access to all records concerning himself; and
- (j) Unless limited by prior court order, to exercise all civil rights, including the right to dispose of property, except property described in subsection (e) of this section, execute instruments, make purchases, enter into contractual arrangements, and vote.

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

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

23 3. PRACTICAL CONSIDERATIONS FROM THE FOREGOING

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

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

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

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

1 guardian. Decisions by the person with disability are not covered by those provisions in 66-405.

2 Third, be aware that, under current practice, there is a great tendency to have a full appointment even
3 when the person has the ability to make decisions in many areas. Therefore, many guardians actually treat
4 the guardianship as if it were a limited guardianship, allowing the ward to make many of their own
5 decisions. This can create ambiguities when you are dealing with the person without the guardian present.
6 You should have procedures in place whenever a person under guardianship is either admitted or providing
7 information to ascertain whether a guardianship is in place, if so what form of guardianship is in place
8 (limited or general), and if possible to discuss with the guardian whether the ward actually has the ability
9 to make some, all, or no medical decisions. The guardian, like a medical agent under a durable power of
10 attorney for health care, is to follow the known wishes of the ward, including their latest authentic
11 expressed wishes.

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

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

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

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



U.S. Department of Justice
Civil Rights Division

EXAMPLES AND RESOURCES TO SUPPORT CRIMINAL JUSTICE ENTITIES IN COMPLIANCE WITH TITLE II OF THE AMERICANS WITH DISABILITIES ACT

The legal requirements this guidance discusses are restatements of existing requirements from Title II of the Americans with Disabilities Act, 42 USC 12131-12134, and its implementing regulations at 28 CFR pt. 35. If you have questions about these requirements, please contact the Civil Rights Division's [ADA Information Line](#).

Title II of the Americans with Disabilities Act (ADA) protects individuals with mental health disabilities and intellectual and developmental disabilities (I/DD) from discrimination within the criminal justice system. Pursuant to the ADA, state and local government criminal justice entities—including police, courts, prosecutors, public defense attorneys, jails, juvenile justice, and corrections agencies—must ensure that people with mental health disabilities or I/DD are treated equally in the criminal justice system and afford them equal opportunity to benefit from safe, inclusive communities. Nondiscrimination requirements, such as providing reasonable modifications to policies, practices, and procedures and taking appropriate steps to communicate effectively with people with disabilities, also support the goals of ensuring public safety, promoting public welfare, and avoiding unnecessary criminal justice involvement for people with disabilities.

The ADA also requires State and local governments to avoid discriminating against people with mental health disabilities or I/DD in administering services, and to serve people with these disabilities in the most integrated setting appropriate to their needs. Effective implementation of these requirements will help people with these disabilities receive the community-based services they need. Furthermore, increased collaboration and improved resource allocation between criminal justice agencies and disability service systems can also help reduce the social, vocational, economic, and educational disparities people with disabilities experience. This document highlights opportunities to increase ADA compliance and positive community outcomes through improved policies, effective training, use of data, resource allocation, and collaboration between criminal justice entities and disability service systems. The Department of Justice hopes this technical assistance will promote the safety and welfare of both individuals with disabilities and criminal justice personnel.

I. General ADA Requirements

Title II of the ADA provides that no qualified individual with a disability shall, because of that disability, be excluded from participation in, denied the benefits of, or subjected to discrimination in the services, programs, and activities of all state or local government entities,

including law enforcement, corrections, and justice system entities. Such services, programs, and activities include:

- Interviewing and questioning witnesses, victims, or parties, negotiating pleas, assessing individuals for diversion programs, conducting arraignment, setting bail or conditions of release, taking testimony, sentencing, providing notices of rights, determining whether to revoke probation or parole, or making service referrals, whether by prosecutors and public defense attorneys, courts, juvenile justice systems, pre-trial services, or probation and parole services;
- Jail and prison intake and classification evaluations, medical and mental health services, recreational activities, educational and vocational programs, rehabilitative programs, grievance procedures, incentive programs, disciplinary and classification proceedings, housing placements, parole and release programs, and re-entry planning; and
- Law enforcement street interactions, taking and responding to complaints or calls for assistance, vehicle stops and searches, arrests, detentions, interviews, interrogations, and emergency responses.

Title II's general prohibitions against discrimination are subject to limitations. When an individual poses a "direct threat" to the health or safety of others, i.e., a significant health or safety risk that cannot be mitigated or eliminated by a reasonable modification of policies, practices or procedures, Title II does not require a public entity to permit that individual to participate in, or benefit from, services, programs, or activities.

The Department highlights below some key Title II obligations for state and local government entities. Every agency and justice system is unique, and state and local leaders are the ones who determine the most effective implementation strategies for their agencies. Therefore, to support state and local law enforcement, corrections, and justice systems leaders in complying with these ADA requirements, each ADA obligation is followed by compliance examples. These examples reflect many of the experiences of state and local leaders around the country who have implemented these strategies to comply with the ADA.

Under Title II, state and local government entities must, among other obligations:

- Ensure that people with mental health disabilities or I/DD have an equal opportunity to participate in and benefit from the entities' programs, services, and activities.
 - Examples of how local law enforcement, corrections, and justice system leaders have facilitated compliance with this obligation:
 - Trained law enforcement officers not to arrest or use force on people with mental health disabilities or I/DD for offenses for which they typically do not arrest or use force on people without disabilities.

- Developed non-discriminatory eligibility criteria for diversion programs such as community services, specialty courts, or probation programs.
 - Developed non-discriminatory eligibility criteria for early release, parole, or other re-entry programs.
- Make reasonable modifications in policies, practices, or procedures when necessary to avoid disability discrimination in all interactions with people with mental health disabilities or I/DD, unless the modifications would fundamentally alter the nature of the service, program, or activity. The reasonable modification obligation applies when an agency employee knows or reasonably should know that the person has a disability and needs a modification, even where the individual has not requested a modification, such as during a crisis, when a disability may interfere with a person's ability to articulate a request. Exigencies and safety considerations play a significant role in determining whether a modification is reasonable. Officers need not make modifications that would interfere with their ability to respond to a safety threat, as such modifications would not be reasonable.
 - Examples of how local law enforcement, corrections, and justice system leaders have facilitated compliance with this obligation:
 - Trained law enforcement officers that, when responding to a person in mental health crisis who does not pose a significant safety threat, they should consider providing time and space to calm the situation. Trained officers that, if available and appropriate, they should dispatch a crisis intervention team or officers trained in de-escalation techniques to the scene, or involve mental health professionals.
 - Required court staff to explore reasonable modifications to allow qualified individuals with these disabilities to participate in diversion and probation programs and specialty courts.
 - Implemented policies that, in situations where a prisoner with these disabilities exhibits negative or disruptive behavior that does not pose a significant safety threat, encourage staff to seek assistance from prison-based crisis intervention teams and mental health professionals, involve officers trained in the use of de-escalation techniques, or forego discipline and provide treatment where it is apparent that a prisoner's behavior was related to a disability.
- Take appropriate steps to ensure that communication with people with disabilities is as effective as communication with people without disabilities, and provide auxiliary aids and services when necessary to afford an equal opportunity to participate in the entities' programs or activities. Even when staff take affirmative steps to ensure effective communication, not everyone will understand everything in the same way and there will necessarily be a spectrum of comprehension across the population based on many factors, including but not limited to age, education, intelligence, and the nature and severity of a

disability. Public entities are not required to take any action that would result in a fundamental alteration in the nature of a service, program, or activity, or undue financial and administrative burdens.

- Example of how local law enforcement, corrections, and justice system leaders have facilitated compliance with this obligation:
 - Trained staff and officers to use effective communication methods, such as using simple language to convey an oath or question, checking understanding by asking people to explain the communication in their own words, giving people time to read documents, or providing or allowing assistive technology, such as a tablet or picture board.
- Administer services, programs, and activities, including disability services, in the most integrated setting appropriate to the needs of qualified individuals with disabilities. Integrated settings allow people with disabilities to interact with people without disabilities to the fullest extent possible.
 - Examples of how local law enforcement, corrections, and justice system leaders have facilitated compliance with this obligation:
 - Established prison classification and placement procedures that generally place prisoners with disabilities in facilities offering the same programs and opportunities as prisoners without disabilities. Provided prisoners with mental health disabilities or I/DD with the services necessary to permit them to reside and participate in the same programs as prisoners without disabilities.
 - Adopted policies to avoid unnecessarily placing prisoners with mental health disabilities or I/DD in restrictive housing, limited the time these prisoners remain in restrictive housing, provided treatment and enhanced opportunities for out-of-cell therapeutic activities, and continuously monitored the mental health of prisoners in restrictive housing. Also made reasonable modifications to conduct rules and disciplinary, classification, and restrictive housing hearings to help limit the number of prisoners with these disabilities unnecessarily placed in restrictive housing.

Public entities may not:

- Use methods of program administration, including written rules and agency practices that have a discriminatory effect on people with disabilities.
 - Example of how local law enforcement, corrections, and justice system leaders have facilitated compliance with this obligation:
 - Trained and supervised corrections staff to conduct screening interviews of all prisoners upon admission to help identify prisoners with mental health disabilities or I/DD.

- Impose eligibility criteria that screen out people with disabilities from their programs, unless the criteria are necessary for the program.
 - Examples of how local law enforcement, corrections, and justice system leaders have facilitated compliance with this obligation:
 - Forbade use of non-essential eligibility criteria in diversion or re-entry programs that courts or corrections operate, mandate, or contract with.

II. Systemic Considerations

It is important that criminal justice entities anticipate and prepare for the disability-related needs of people with mental health disabilities or I/DD. Training criminal justice personnel, conducting reviews of policies and procedures, and collaborating with mental health and disability services providers are three ways to achieve that end.

A. Training

Criminal justice personnel are likely to encounter people with mental health disabilities or I/DD who are part of the communities they serve and protect. Several factors may indicate that a person has a mental health disability or I/DD, including self-report, information provided to dispatch or to the officer or employee, the employee's prior knowledge of the person, or the employee's direct observation. Without proper training, criminal justice personnel may misinterpret the conduct of individuals with mental health disabilities or I/DD as intentional disrespect or disobedience, which may escalate encounters and lead to unnecessary criminal justice involvement. Appropriate training can prepare personnel to execute their ADA responsibilities in a manner that keeps staff, individuals with disabilities, and members of the community safe; promotes public welfare; builds trust with the community; respects the rights of individuals with disabilities; ensures effective use of criminal justice resources; and contributes to reliable investigative and judicial results.

Criminal justice entities have provided trainings to their personnel on these topics:

- How non-medically trained criminal justice personnel can recognize common characteristics and behaviors associated with mental health disabilities or I/DD;
- How to interact with individuals with these disabilities;
- When and how to make reasonable modifications for individuals with these disabilities;
- What individuals with these disabilities may experience and how that may affect their interactions with others (*e.g.*, hearing voices);
- How to take appropriate steps to ensure effective communication with individuals with mental health disabilities or I/DD;
- How to avoid escalating interactions with people with these disabilities;
- How to use de-escalation or other alternative techniques to increase safety and avoid using force unnecessarily;
- What local resources are available to provide treatment, services, or support for individuals with mental health disabilities or I/DD; and

- When and how to draw upon these resources or others, such as crisis intervention teams, mobile crisis teams, assertive community treatment teams, or mental health providers.

Special Considerations for Law Enforcement Agencies: Law enforcement agencies have provided training to dispatchers on how to recognize and handle calls from or about people with mental health disabilities or I/DD, including on the following topics:

- The availability of crisis intervention teams or other resources to respond to calls about individuals with mental health disabilities or I/DD;
- When to dispatch crisis intervention teams or officers with training in interacting with people with these disabilities;
- When to consider dispatching a mental health provider rather than a police officer;
- Information about, and contact information for, community-based service providers; and
- The importance of communicating information dispatchers receive about individuals' disabilities to responding officers or service providers.

B. Analysis

Criminal justice entities have reviewed their policies, practices, procedures, and standing orders to ensure that they do not discriminate against people with mental health disabilities or I/DD. For example, entities have collected, aggregated, and analyzed data regarding individuals served by the entity and outcomes to determine whether people with disabilities are subjected to bias or other discrimination. Where potential discrimination has been found, entities have taken necessary corrective measures, such as revising policies and procedures; refining quality assurance processes; and implementing training.

C. Collaboration with Other Entities

States, counties, and cities, which often administer both criminal justice and disability service systems, have obligations under the ADA to ensure people with mental health disabilities or I/DD receive services in the most integrated setting appropriate to their needs. Services such as [scattered-site supported housing](#), [Assertive Community Treatment \(ACT\)](#), [crisis services](#), [intensive case management](#), [respite](#), [personal care services](#), [behavior support](#), [nursing care](#), [peer support](#), and [supported employment services](#) can support a jurisdiction's efforts to divert people with these disabilities from the criminal justice system and serve them in their communities.

State and local governments must prevent unnecessary institutionalization of people with disabilities. Governments have complied with this obligation by using community-based treatment services to keep people with disabilities out of the criminal justice system. These governments have recognized that the responsibility for effectively serving people with mental health disabilities or I/DD cannot fall to law enforcement alone. Therefore, they ensure that their disability service systems offer sufficient community-based services and support criminal justice entities to coordinate with, and divert to, community-based services.

Criminal justice entities have collaborated with their jurisdiction's mental health and disability services programs and with service providers on the following:

- Ensuring that law enforcement officers have contact information for relevant service providers and developing policies for when dispatchers or law enforcement officers should contact mental health service providers rather than engage in arrests.
- Helping individuals with these disabilities access community-based services. Federal resources may be available to help individuals connect with and participate in these services. When release conditions include finding housing and employment, agencies have prepared their staff to facilitate access to community-based supported housing and employment services or have modified such conditions when needed to avoid discrimination.
- Facilitating Medicaid or health insurance enrollment for prisoners with disabilities, identifying community-based service providers, and collaborating with providers to complete intake interviews and schedule initial appointments before release.¹
- Developing policies, procedures, and training on diversion, de-escalation, release planning, use of force, and discipline.

III. Resources

A. Examples of Policies and Practices That Facilitate ADA Compliance

Department of Justice settlement agreements provide examples of policies and procedures that assist in achieving ADA compliance in key areas.

Crisis Response: Through settlement agreements with the Department, police departments in [Portland](#) and [Seattle](#) trained additional officers to serve on Crisis Intervention Teams (CIT). Also, all officers in these jurisdictions now receive basic training on effectively interacting with people with mental health disabilities and on crisis de-escalation. The [New Orleans Police Department](#) and the [Portland Police Bureau](#) developed CIT [policies](#) that encourage de-escalation, diversion, and coordination with the local mental health agency. Portland also developed a comprehensive [Behavioral Health Unit](#) that includes multiple co-responder teams that pair a specially trained police officer with a mental health professional to divert frequent users of police services based on their mental health needs.

Use of Force: Agencies have revised use-of-force policies and training after the Department found a pattern of unreasonable use of force, including on people with mental health disabilities. For example, Seattle revised its [use-of-force training curriculum](#) and policy to emphasize

¹ Federal resources may be available to help agencies offset the costs of Medicaid-related activities. Moreover, incarceration does not preclude a prisoner from being determined Medicaid eligible, even while Medicaid is suspended during incarceration.

conducting threat assessments, determining whether behaviors are disability-related, using CIT whenever feasible, and using de-escalation techniques such as time, distance, and shielding.

Diversion and Coordination with Mental Health Providers: A [settlement agreement](#) in Portland led to the creation of a crisis center available to first responders seeking to divert individuals with disabilities from the criminal justice system into the community mental health system. Portland and New Orleans have implemented policies to transport these individuals to treatment by [ambulance](#) or [civilian services](#) in lieu of police vehicles. Similarly, police departments across Delaware can now refer people in mental health crisis to community-based [Crisis Intervention Services](#). Delaware created these alternatives to meet their responsibility under the ADA under a [settlement agreement](#) with the Department.

In a [settlement agreement](#) with Hinds County, Mississippi regarding its jail, the Department and County agreed to “work toward the goal of population reduction in a manner that preserves public safety, prioritizes diversion for unnecessary criminal justice involvement, and reduces recidivism,” particularly for individuals with mental health disabilities. Hinds County agreed to establish a criminal justice coordinating committee to enhance coordination between criminal justice and mental health agencies to prevent unnecessary arrest and detention and connect individuals with disabilities to mental health services. Agreements in both [Delaware](#) and [New Hampshire](#) target community-based mental health services at individuals with mental illness who have histories of involvement in the criminal justice system to prevent recidivism.

A settlement in [Tennessee](#) led to statewide [training](#) of law enforcement officers on interacting with people with I/DD.

Release Planning: The [settlement agreement](#) with Hinds County, Mississippi requires the jail to notify community mental health providers when releasing a prisoner with serious mental illness so the prisoner can transition safely to the community. To aid in transition, the jail will provide prisoners with details related to a follow up appointment at the relevant mental health center and give them sufficient medications to cover the period until the scheduled appointment.

Restrictive Housing (Solitary Confinement): In a [settlement](#), Ohio agreed to reduce its reliance on seclusion for juveniles on the mental health caseload at its secure juvenile facilities by limiting the bases for placing juveniles in seclusion and reducing the time period any juvenile spends in seclusion. Ohio eventually [eliminated the use of disciplinary seclusion](#) at its juvenile facilities. Similarly, in response to Department of Justice [findings](#), Pennsylvania [revised its policies](#) to divert prisoners with serious mental health or developmental disabilities from solitary confinement and into treatment units.

Disciplinary Proceedings: The Pennsylvania Department of Corrections [modified its policies and procedures](#) to require that prisoners with serious mental health or developmental disabilities be evaluated by mental health staff to consider mitigated sanctions if they are subject to serious misconduct sanctions and to resolve allegations of non-violent offenses informally. In addition, the policies no longer permit discipline for self-injurious behavior.

B. Case Findings and Remedies

Law Enforcement

- [Baltimore, MD Police Department](#)
- [Portland, OR Police Bureau](#)
- [Cleveland, OH Division of Police](#)
- [Ferguson, MO Police Department](#)
- [Albuquerque, NM Police Department](#)
- [Seattle, WA Police Department](#)
- [New Orleans, LA Police Department](#)

Corrections and Juvenile Detention Facilities

- [Ohio Department of Youth Services](#)
- [Hinds County, MS Jail](#)
- [Pennsylvania State Correctional Institution at Cresson](#)
- [Leflore County, MS Juvenile Detention Center](#)

Community-Based Services

- [Delaware](#)
- [Georgia](#)
- [New Hampshire](#)
- [North Carolina](#)
- [Virginia](#)

C. Additional Resources

- General requirements of Title II of the ADA - [ADA Title II Technical Assistance Manual](#).
- How Title II applies to law enforcement agencies - [Commonly Asked Questions about the ADA and Law Enforcement](#).
- Title II's effective communications requirement - [ADA Title II Technical Assistance Manual](#) and [ADA Update: A Primer for State and Local Governments](#).
- Integration obligations of state and local disability service systems - [Statement on Enforcement of the Integration Mandate of Title II of the ADA and Olmstead v. L.C.](#)
- Resources to help officers respond appropriately to people with mental illness - Bureau of Justice Assistance's [Police-Mental Health Collaboration Toolkit](#).
- Alternatives to incarceration - DOJ Office of [Community Oriented Policing Services](#).
- Diversion - The Substance Abuse and Mental Health Services Administration's (SAMHSA) GAINS Center for Behavioral Health and Justice Transformation.

- Specialty courts - [Bureau of Justice Assistance](#) and SAMHSA's [Behavioral Health Treatment Court Collaboratives](#).
- Alternatives to seclusion and restraint - SAMHSA's [National Center for Trauma-Informed Care and Alternatives to Seclusion and Restraint](#) and DOJ's [Report and Recommendations Concerning the Use of Restrictive Housing](#).

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ETHICAL CONSIDERATIONS IN DEVELOPMENTAL DISABILITY AND THE IDAHO RULES OF PROFESSIONAL CONDUCT

The following is a very brief outline of some of the Rules that may be involved in representation of a client who has a Developmental Disability. I have included only the bare minimum portion of the Rule and no Comments when possible.

1. Rule 1.1 Competence.

RULE 1.1: COMPETENCE A lawyer shall provide competent representation to a client. Competent representation requires the legal knowledge, skill, thoroughness and preparation reasonably necessary for the representation.

Any attorney dealing with incapacity had better fully understand the ramifications of *Rogers* and *Conway*, and of conservatorship and guardianship generally, including the alternatives available and mandated. Further, the attorney should be very familiar with the recent updates in the statutes, including both House Bill 148 and Senate Bill 10190 (both attached). And, given the severe consequences of a general guardianship after *Rogers*, the attorney should be equipped and ready to analyze whether a limited or general guardianship should be sought, or any formal proceeding at all, and what are appropriate limitations.

2. Rule 1.2 Scope of Representation.

RULE 1.2: SCOPE OF REPRESENTATION (a) Subject to paragraphs (c) and (d), a lawyer shall abide by a client's decisions concerning the objectives of representation and, as required by Rule 1.4, shall consult with the client as to the means by which they are to be pursued. A lawyer may take such action on behalf of the client as is impliedly authorized to carry out the representation. A lawyer shall abide by a client's decision whether to settle a matter.

When can you "abide by a client's decisions" and consult with the client about pursuing those decisions in the context of a C&G proceeding? The statutes, both for Developmental Disability and for probate code proceedings, makes it clear, at least to me, that a person for whom a proceeding has been brought has the right to counsel and this counsel is not only the Guardian ad Litem. When does your attorney-client relationship cease? If incapacity removes the ability of the attorney to communicate with the client, does the representation cease? Can you enter an appearance as attorney of record for the client in the appointment procedures and does that depend on the nature of your prior representation and fee agreements, written or oral or established by conduct?

3. Rule 1.4 Communication.

RULE 1.4: COMMUNICATION (a) A lawyer shall: (1) promptly inform the client of any decision or circumstance with respect to which the client's informed consent, as defined in Rule 1.0(e), is required by these Rules; (2) reasonably consult with the client about the means by which the client's objectives are to be accomplished; (3) keep the client reasonably informed about the status of the matter;

You must consult with the client about any relevant limitation on the lawyer's conduct not permitted by the Rules of Professional Conduct or by "other law". Further you must "keep the client reasonably informed about the status of the matter." What happens upon temporary or permanent

appointment of a guardian or conservator? Do you have a duty to inform the client that you cannot proceed or that you cannot consult with him or her? Or is that appointment irrelevant to your status as attorney for the client? Can you inform the client or consult with the client about the effect of changing a general appointment to a limited appointment? Can you continue with estate planning and so inform the client? What effect does *Rogers* have on this

4. Rule 1.14 Client with Diminished Capacity.

RULE 1.14: CLIENT WITH DIMINISHED CAPACITY (a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client. (b) When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken and cannot adequately act in the client's own interest, the lawyer may take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, conservator or guardian. (c) Information relating to the representation of a client with diminished capacity is protected by Rule 1.6. When taking protective action pursuant to paragraph (b), the lawyer is impliedly authorized under Rule 1.6(a) to reveal information about the client, but only to the extent reasonably necessary to protect the client's interests.

Commentary. [1] The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. When the client is a minor or suffers from a diminished mental capacity, however, maintaining the ordinary client-lawyer relationship may not be possible in all respects. In particular, a severely incapacitated person may have no power to make legally binding decisions. Nevertheless, a client with diminished capacity often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being. For example, children as young as five or six years of age, and certainly those of ten or twelve, are regarded as having opinions that are entitled to weight in legal proceedings concerning their custody. So also, it is recognized that some persons of advanced age can be quite capable of handling routine financial matters while needing special legal protection concerning major transactions.

[2] The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client with attention and respect. Even if the person has a legal representative, the lawyer should as far as possible accord the represented person the status of client, particularly in maintaining communication.

This is the prime Rule in dealing with clients who have any diagnosis that may, and I stress the may, indicate diminished capacity. A diagnosis of developmental disability does not automatically mean diminished capacity. In fact many of the spectrum of conditions that are labeled as a developmental disability have no effect on capacity. The attorney must be ready to take whatever steps are necessary to determine whether the client has capacity and not make assumptions either way. Often, a discussion with the client, properly done, can accomplish that. You must be careful not to just ask questions that can be answered "yes-no". Make the client come up with narrative answers that require an appreciation of the issues involved and an understanding of the basic concepts. Some clients become very good at what I call "cocktail party talk" – you can't understand or even hear a word the other person is saying, but you have learned how to nod and make non-

committal sounds of affirmation at the appropriate times. But don't expect the client to have a lawyer's appreciation of the complexities of the legal process. And remember that capacity is measured differently for different types of matters – estate planning is pretty low, while entering into complex financial transactions (e.g. negotiating a complex sale or purchase of a business) is much higher.

A temporary appointment of a guardian or conservator made without hearing is not a finding that the person has diminished capacity. Due process requires a hearing and notice before any such determination can be made. And remember that the fundamental purpose of appointment of a guardian or conservator is to protect the person when they might otherwise be damaged. Some people with full capacity have an inability to say no to a family member, or a friend, who will bleed them dry, but otherwise can make rational decisions. I have been involved in such cases. Additionally, as I have testified before two US Senate Committees and multiple times in the Idaho legislature, we have the right to be eccentric and occasionally stupid. End of soap box.

You can, in theory, under this Rule, essentially trigger the appointment of a conservator or guardian for your client. Given *Rogers* and your duty to protect your client, what is your duty to attempt to keep the appointment limited if possible? How do you effectively do that? Does that mandate attempting to appear as attorney of record for the client in the appointment proceedings even if a Guardian ad Litem is appointed? Or should you be the Guardian ad Litem? Should you attempt to create trusts, powers, and so forth to avoid having an appointment made to the extent the client still has capacity to do so? Commentary 8 to this Rule talks about disclosure that could "adversely affect the client's interests." A general appointment certainly could be described as potentially adversely affecting the client's interests, and the Rule may require that the attorney, pursuant to Commentary 8, "at the very least," determine whether the outside person or entity will act adversely to the client's interests.



Service Animal Rules Comparison

I. Americans with Disabilities Act (ADA)

What animals are covered?	The ADA defines a service animal as a dog that is individually trained to do work or perform tasks for an individual with a disability. A separate provision also includes certain small horses that are trained to perform tasks. Considerations regarding miniature horses are: (1) whether the miniature horse is housebroken; (2) whether the miniature horse is under the owner’s control; (3) whether the facility can accommodate the miniature horse’s type, size, and weight; and (4) whether the miniature horse’s presence will not compromise legitimate safety requirements necessary for safe operation of the facility.
Is an emotional support animal covered?	No. A comfort or emotional support animal is not considered trained. Therefore the ADA does not require covered entities to admit a comfort animal if there is a “no pets” policy.
Is a service animal-in-training covered?	No. The ADA does not address a service animal-in-training, but rather gives each state the right to make its own laws regarding providing a reasonable accommodation for a service animal-in-training.
What entities must allow the service animal access to accompany the person with a disability?	Title I of the ADA covers employers with at least 15 employees. Employers must provide reasonable accommodations to employees with disabilities which could include allowing a service animal at the place of employment. Title II of the ADA covers state and local governments. Title III of the ADA covers public accommodations. Public accommodations include most businesses, although religious entities are excluded.
Is training and/or proof of training for the service animal required?	Yes. Under the ADA, a service animal must be a dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability. Service animals can be professionally trained or trained by the user.
Is certification for the service animal required?	No. Under Title II and Title III, a service animal handler does not need to provide certification.

Is medical documentation for the disability required?	Generally no. Under Title I of the ADA, if an employee requests a service animal a reasonable accommodation at the place of employment, medical documentation of disability may be requested by the employer.
When can a service animal be excluded?	An animal can only be denied access if the animal is out of the control of the handler; the animal is not housebroken; or the animal poses a direct threat to others that cannot be lessened. The threat must be evidenced by the actual behavior of the animal.
Who is responsible for damages?	The handler of the service animal is responsible for any damages resulting from the dog's behavior.
What remedies are available?	ADA Title II and Title III: Complaints can be filed with the U.S. Dept. of Justice. ADA Title III: Complaints can be filed with the U.S. Dep. of Justice at any time. ADA Title I: Complaints can be filed with the Equal Employment Opportunity Commission. Complaints should be filed within 180 days under Titles I and II. In addition, the Idaho Human Rights Commission will accept complaints regarding state law violations of service animal access by public accommodations. Court remedies are available under all ADA titles.

Citations: 28 CFR Parts 35 and 36. Also refer to: U.S. Department of Justice's ADA website at www.ada.gov.

II. Fair Housing Act (FHA)

What animals are covered?	The FHA does not contain a definition of service animal. The U.S. Dept. of Housing and Urban Development (HUD) uses the term assistance animal to clarify that the FHA includes both service animals performing tasks and emotional and therapy support animals.
Can a tenant request to keep an emotional support animal?	Yes. According to HUD, a reasonable accommodation of a "no pets" policy must be made for any assistance animal if a tenant has a disability and a disability-related need for the assistance form the animal.
Are assistance animals-in-training covered?	Yes. The FHA does not require an animal to be trained. Therefore, service animals-in-training could be allowed as a reasonable accommodation under the FHA.
What housing is covered by the FHA?	The FHA covers most types of long term housing, but does not cover homes owned by a single family or small units where a landlord also resides. The ADA prevents discrimination in short term lodging, such as motels.
Is documentation of training for the assistance animal required?	No. The FHA does not require training for an assistance animal. Therefore, a landlord can not require certification or proof of training.

Is medical documentation of the disability required?	Sometimes. If a need for the assistance animal is not obvious, a landlord may request medical documentation that a tenant has a qualifying disability and ask what assistance the animal provides based upon this disability.
What is the housing provider required to do?	The FHA makes it unlawful for any person to refuse “to make reasonable accommodations in rules, policies, practices, or services, when allowing a service animal would be necessary to afford a person with a disability an equal opportunity to use and enjoy a dwelling.” Therefore a housing provider would have to make an accommodation in a no pets policy for an assistance animal for a tenant if required under this standard.
When can a request for a reasonable accommodation for an assistance animal be denied?	A landlord can deny the request for an assistance animal if: (1) the specific assistance animal in question poses a direct threat to the health or safety of others that cannot be reduced or eliminated by another reasonable accommodation, or (2) the specific assistance animal in question would cause substantial physical damage to the property of others that cannot be reduced or eliminated by another reasonable accommodation. The request can also be denied if it is an undue administrative or financial burden to the landlord or a fundamental alteration of the nature of the housing.
Can the landlord request a pet deposit for the assistance animal?	No. A reasonable accommodation may not be conditioned upon paying a pet deposit since the animal is not a pet.
Who is responsible for damages caused by the assistance animal?	A landlord may ask a tenant to pay for the repairs for damage the animal causes to the tenant's dwelling unit or common areas, reasonable wear and tear excepted, if other tenants must also pay for any damage they cause.
What remedies are available?	The person may file a complaint with HUD within one year of the alleged denial. HUD will investigate at no cost to the complainant. The person may also file a lawsuit in district court if within two years of the incident. The Intermountain Fair Housing Council can provide further information on remedies.

Citations: 24 CFR §§ 8.11, 8.20, 8.21, 8.24, and 8.33 and 24 CFR §§ 960.705, 100.202 and 100.204.

Also refer to: HUD’s FHEO Notice # FHEO-2013-01: Service Animals for People with Disabilities in Housing and HUD-Funded Programs; and HUD’s Final Rule on Pet Ownership for the Elderly and People with Disabilities, 24 CFR § 5.303; and HUD’s *Letter to FHEO Region Directors*, “New ADA Regulations and Assistance Animals as Reasonable Accommodations under the Fair Housing Act and Section 504 of the Rehabilitation Act of 1973, dated February 17, 2011.

III. Air Carrier Access Act (ACAA)

What animals are covered?	The ACAA refers to a “service animal,” defined as any guide dog, signal dog, or other animal individually trained to provide assistance to an individual with a disability. Not every animal has to be accepted if it is too large, heavy, unusual or a threat.
Is an emotional support animal covered?	Some. An emotional support animal can be covered if a mental health professional confirms in a current letter on letterhead with licensing credentials that the health professional is treating the person travelling for a DSM-IV mental health diagnosis and that the animal is needed for air travel or an activity at the destination. The actual diagnosis does not have to be disclosed.
Is a service animal-in-training covered?	No. Since the animal is not yet trained, the animal does not meet the definition. Individual carriers, however, may have policies that allow a service animal-in-training.
What air carriers are covered?	U.S. and foreign air carriers and their employees (e.g., ticket and gate agents, flight attendants, baggage handlers, or pilots); authorized agents of an air carrier (e.g., travel agents); organizations and their employees that have business arrangements with air carriers to provide disability-related services (e.g., wheelchair service or baggage handling); and indirect air carriers and their employees (e.g., tour operators) that provide facilities, services, or other accommodations to passengers with disabilities. If the alleged discrimination occurs in an airport facility, it is covered by the ADA and not the ACAA.
What must the air carriers allow?	A service animal must be allowed to accompany a passenger on the flight to the passenger’s assigned seat and remain there as long as the animal does not obstruct the aisle or other areas that must remain unobstructed for safety reasons.
Is training and/or proof of training required?	Yes. The animal must be trained to meet the definition. Certification is not required and any type of documentation or “the credible verbal assurances of a qualified individual with a disability using the animal” should be accepted.
Is medical documentation of disability required?	Not usually. Air carriers may ask for documentation, but if the animal has a harness or tag that should be accepted as documentation. Air carriers may also obtain credible verbal assurances from passengers who have service animals that the animal is a trained service animal. If the verbal assurance does not seem credible, the carrier may ask for medical documentation. Documentation may be required for an emotional support animal as noted above.
Is notice of travel with a service animal required?	Maybe. Notice of travel with a service animal is not required unless the flight is longer than 8 hours. Emotional support animals require 48 hour advance notice.
Is special seating required?	No. The passenger and animal are entitled to sit in the bulkhead area but are not required to. The animal cannot block the aisles. If new seating is required, the carrier should offer to relocate the passenger and animal rather than require the animal to be transported in the cargo area.

When can a service animal be moved or excluded?	The service animal must be allowed to accompany the passenger unless it poses a direct threat to the health or safety of others or presents a significant threat of disruption to the airline service in the cabin.
Can extra fees be charged?	No. The airline cannot require extra deposits or fees for damages unless could be charged to other passengers also.
What remedies are available?	Complaints can be filed with the Aviation Consumer Protection Division of the U.S. Dept. of Transportation. The Consumer Protection Division has the authority to order the carrier to rectify the denial and assess a civil penalty, but will not seek money damages for the claimant. The ACAA does not specifically provide for individual lawsuits and some case law suggests that a lawsuit in federal court may not be allowed.

Citations: 49 USC § 41705 and 14 CFR Part 382

Also refer to: Appendix VI: DOT Guidance Concerning Service Animals in Air Transportation; and FAA Flight Standards Information Bulletin for Air Transportation (FSAT) #04-01A, “Location and Placement of Service Animals on Aircraft Engaged in Public Air Transportation.”

IV. Idaho Code

What animals are covered?	Idaho law defines an assistance dog as a dog that has been trained as a guide dog for a person who is blind or has a vision disability, a hearing dog for a person with a hearing disability, or as a service dog for a person with a physical disability.
Are emotional support animals covered?	No. Emotional support animals are not included in the definition of assistance dog.
What entities must provide access to the assistance animal?	Idaho law gives persons with disabilities the right to full and equal accommodations in all common carriers, hotels, lodging houses, places of public accommodation or other public places.
What must a covered entity allow?	Idaho law grants the right to be accompanied by an assistance animal in any covered entity.
Is training and/or proof of training required?	Perhaps. According to Idaho Code, an “assistance dog” is one that has been trained. If the dog’s training is not obvious, it may be reasonable for a person to ask for documentation that the animal is trained. The Idaho Code does not require that the animal be certified and proof of training could be provided by another means. The dog is also not required to wear any special identifying clothes or tags.
Is medical documentation required?	No. The Idaho Code does not require documentation or identification. If the need for the assistance animal is not obvious, it may be reasonable for a person to ask how the animal assists the person.

Is a service animal-in-training covered?	Yes. Idaho law specifically recognizes that every person who is specially training or socializing a dog to become an assistance dog has the right to be accompanied by the dog in public places. A dog-in-training is required to wear a jacket, collar, scarf or other similar article to identify it as a dog-in-training. The person who is training the dog is required to have an identification card from the training program.
Who is responsible for damages?	Idaho law requires that the person with a disability be responsible for any damages caused by an assistance dog or assistance dog-in-training. The person can not be required to pay an extra charge for allowing the assistance animal however.
What remedies are available?	Interference with a person's rights under Idaho Code Title 56, Chapter 7 is a misdemeanor and Idaho's criminal code states that "any person, firm, association or corporation or agent of any person, firm, association or corporation" who interferes with or intentionally denies access to an assistance dog "shall be guilty of a misdemeanor." Therefore, the local police could be contacted to investigate the incident. Idaho law allows for a civil lawsuit against the person or entity denying access to the assistance animal and punitive damages of at least \$500 may be awarded, in addition to other provable damages, to the person with a disability if the claim is successful. A two year statute of limitations to file the lawsuit may apply. The Idaho State Bar Association can provide a referral to an attorney to file a civil lawsuit or the Idaho Court Assistance Office can provide advice on filing a complaint in court.

Citations: Idaho Code §§ 56-701-706 and Idaho Code §§ 18-5811-5812.

For more information contact:

**DisAbility Rights Idaho toll free at 1-866-262-3462
Northwest ADA Center – Idaho at 1-208-841-9422
Intermountain Fair Housing Council at 1-208-383-0695 or 1-800-717-0695.**

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JAN

Job Accommodation Network

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Accommodation and Compliance Series

Service Animals in the Workplace

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Office of Disability
Employment Policy

A service of the U.S. Department of Labor's Office of Disability Employment Policy

Preface

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Authored by Linda Carter Batiste, J.D. Updated 06/17/11.

JAN'S ACCOMMODATION AND COMPLIANCE SERIES

Introduction

JAN's Accommodation and Compliance Series is designed to help employers determine effective accommodations and comply with title I of the Americans with Disabilities Act (ADA). Each publication in the series addresses a specific medical condition or topic and provides information about the condition or topic, ADA information, accommodation ideas, and resources for additional information.

The Accommodation and Compliance Series is a starting point in the accommodation process and may not address every situation. Accommodations should be made on a case by case basis, considering each employee's individual limitations and accommodation needs. Employers are encouraged to contact JAN to discuss specific situations in more detail.

For information on assistive technology and other accommodation ideas, visit JAN's Searchable Online Accommodation Resource (SOAR) at <http://AskJAN.org/soar>.

Information about Service Animals

What is a service animal?

A service animal is an animal that performs a task or tasks for a person with a disability to help overcome limitations resulting from the disability. Federal law defines service animal as "any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability. Other species of animals, whether wild or domestic, trained or untrained, are not service animals for the purposes of this definition. The work or tasks performed by a service animal must be directly related to the individual's disability" (DOJ, n.d.).

What types of work or tasks do service animals perform?

According to the Department of Justice (n.d.), "examples of work or tasks include, but are not limited to, assisting individuals who are blind or have low vision with navigation and other tasks, alerting individuals who are deaf or hard of hearing to the presence of people or sounds, providing non-violent protection or rescue work, pulling a wheelchair, assisting an individual during a seizure, alerting individuals to the presence of allergens, retrieving items such as medicine or the telephone, providing physical support and assistance with balance and stability to individuals with mobility disabilities, and helping persons with psychiatric and neurological disabilities by preventing or interrupting impulsive or destructive behaviors. The crime deterrent effects of an animal's presence and the provision of emotional support, well-being, comfort, or companionship do not constitute work or tasks for the purposes of this definition."

What is the difference between service, therapy, companion, and social/therapy animals?

According to the Delta Society, a human-services organization dedicated to improving people's health and well-being through positive interactions with animals:

Service animals are legally defined under title III of the Americans with Disabilities Act and are trained to meet the disability-related needs of their handlers who have disabilities. The ADA protects the rights of individuals with disabilities to be accompanied by their service animals in public places. Service animals are not considered 'pets' (Delta Society, n.d.).

Therapy animals are not legally defined by federal law, but some states have laws defining therapy animals. They provide people with contact to animals, but are not limited to working with people who have disabilities. They are usually the personal pets of their handlers, and work with their handlers to provide services to others. Federal laws have no provisions for people to be accompanied by therapy animals in places of public accommodation that have "no pets" policies. Therapy animals usually are not service animals (Delta Society, n.d.).

A companion animal is not legally defined, but is accepted as another term for pet (Delta Society, n.d.).

Social/therapy animals have no legal definition. They often are animals that did not complete service animal or service dog training due to health, disposition, trainability, or other factors, and are made available as pets for people who have disabilities. These animals might or might not meet the definition of service animals (Delta Society, n.d.).

Service Animals and the Americans with Disabilities Act

Because more people are using service animals, employers are asking more questions about service animals in the workplace. The following is a summary of some of those questions. The answers are based on informal guidance from the Equal Employment Opportunity Commission (EEOC) and do not represent the EEOC's formal position on these issues or legal advice.

Does title I of the ADA require employers to automatically allow employees with disabilities to bring their service animals to work?

Title III (public access) of the ADA requires a public accommodation to modify policies, practices, or procedures to permit the use of a service animal by an individual with a disability (DOJ, n.d.). Title III also requires public accommodations to make reasonable modifications in policies, practices, or procedures to permit the use of a miniature horse

by an individual with a disability if the miniature horse has been individually trained to do work or perform tasks for the benefit of the individual with a disability (DOJ, n.d.).

But what about title I (employment) of the ADA? According to the EEOC, title I does not require employers to automatically allow employees to bring their service animals to work. Instead, allowing a service animal into the workplace is a form of reasonable accommodation.

What this means for employers: Employers must consider allowing an employee with a disability to use a service animal at work unless doing so would result in an undue hardship. In addition, the ADA allows employers to choose among effective accommodations, although providing a substitute accommodation for a service animal could bring up other tricky issues (see question 4 below).

What is the definition of service animal under title I of the ADA?

As mentioned previously, title III (public access) regulations define service animal as “any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability. Other species of animals, whether wild or domestic, trained or untrained, are not service animals for the purposes of this definition. The work or tasks performed by a service animal must be directly related to the individual’s disability. Examples of work or tasks include, but are not limited to, assisting individuals who are blind or have low vision with navigation and other tasks, alerting individuals who are deaf or hard of hearing to the presence of people or sounds, providing non-violent protection or rescue work, pulling a wheelchair, assisting an individual during a seizure, alerting individuals to the presence of allergens, retrieving items such as medicine or the telephone, providing physical support and assistance with balance and stability to individuals with mobility disabilities, and helping persons with psychiatric and neurological disabilities by preventing or interrupting impulsive or destructive behaviors. The crime deterrent effects of an animal’s presence and the provision of emotional support, well-being, comfort, or companionship do not constitute work or tasks for the purposes of this definition” (DOJ, n.d.).

But what about title I (employment) of the ADA? According to the EEOC, there is no specific definition of service animal under title I, and title III regulations do not apply to questions arising under title I.

What this means to employers: Because there is not a specific definition of service animal under title I, employers may have to consider allowing an employee to bring in an animal that does not meet the title III definition of service animal, such as a therapy or emotional support animal. However, employers do not have to allow an employee to bring an animal into the workplace if it is not needed because of a disability or if it disrupts the workplace.

What kind of documentation can employers ask for related to a service animal? What if the employee's doctor was not involved in the acquisition of the service animal or the employee trained his own service animal and nobody else was involved so the typical kind of medical documentation that employers ask for is not be available? What might be considered sufficient documentation in this type of situation?

Under the ADA, employers have the right to request reasonable documentation that an accommodation is needed (EEOC, 2002). However, according to informal guidance from the EEOC, employers need to be aware that sometimes reasonable documentation is not always going to be from a doctor or some other health care professional. In some cases the documentation should come from the appropriate provider of a service. In the case of a service animal, the appropriate documentation might be from whoever trained the service animal.

The goal of an employer is to understand why the service animal is needed and what it does for the person, so the training is important. If an employee has a service animal in a workplace where there could be lots of different kinds of distractions, lots of things going on, the employer has the right to require that the service animal be fully trained and capable of functioning appropriately, not just for the employee with the disability, but also in terms of the setting. An employee who trains his or her own service animal needs to be able to document or demonstrate that the service animal is in fact trained and will not disrupt the workplace.

What this means for employers: When an employee with a disability requests to use a service animal at work, the employer has the right to request documentation or demonstration of the need for the service animal, that the service animal is trained, and that the service animal will not disrupt the workplace. However, this documentation may not be available from a healthcare provider so the employer may need to consider other sources for the documentation.

If an employee wants to bring his service animal to work to help with personal medical needs (e.g., an employee with diabetes wants to bring his service animal to work to help monitor his blood sugar level), can the employer deny the request and ask the employee to take care of his medical needs in another way?

According to the EEOC, if the service animal has been trained to help with the employee's medical needs, the employee has a right to ask that, as a reasonable accommodation, the service animal be allowed to accompany him to work.

The employer has a right to know that the animal is actually trained and what the animal does for the employee. However, the employer probably cannot insist that the person take care of his medical needs in a different way if this is the way the employee does it; under the ADA an employer cannot require employees to use other medical treatment/procedures.

What this means for employers: In general, employers should not be involved in employees' personal medical decisions so an employer should not deny an employee's request to use his service animal at work if the animal helps the employee with his or her personal medical needs, unless the employer can show undue hardship.

Who is responsible for taking care of a service animal at work?

The employee is responsible for taking care of the service animal, including making sure the animal is not disruptive, keeping it clean and free of parasites, and taking it out to relieve itself as needed.

What this means for employers: Employees are responsible for the care of their service animals, but employers may have to provide accommodations that enable the employees to do so. When an employee is allowed to bring a service animal to work, the employer should consult with the employee to find out what accommodations are needed to care for the animal. For example, an employee might need to adjust his break times to take his service animal outside.

Do employers have to create a relief area for a service animal when an employee with a disability uses the service animal in the workplace?

The EEOC does not have any formal guidance regarding whether an employer must create an animal relief area for an employee who uses a service animal, but this should rarely be an issue because there is almost always a place outside, close to the work-site, where the animal can relieve itself. For example, the animal could relieve itself in an alley behind the work-site, a grassy area close to the work-site, or even close to a sidewalk leading to the building. Of course the employer could require the employee to clean up after the animal.

To date, the EEOC has not addressed what an employer's obligation would be to create a relief area in the event there is absolutely no existing place for the service animal to relieve itself.

What this means for employers: From a practical standpoint, an employer faced with a request to create a relief area for a service animal might want to consider doing so even though it is not clearly required as an accommodation under the ADA because otherwise the employee is not going to be able to use his or her service animal at work.

Do employers have to allow employees to train service animals in the workplace?

Under the ADA, only employees with disabilities are entitled to reasonable accommodations so if an employee without a disability is training a service animal for someone else, there is no accommodation obligation under the ADA. For employees with disabilities, an employer has a valid concern about the potential disruption a service animal in training might create so might not have to allow the employee to bring

in the service animal until it is fully trained or at least until it can be in the workplace without disruption. Some states have laws addressing access for service animals in training, so employers also should check their state laws.

What this means for employers: When an employee asks to bring in a service animal in training, the employer should check state laws first. If state law does not address access for service animals in training, then the employer should next determine whether the employee who is making the request has a disability and needs the service animal because of the disability. If the employee does have a disability, then the employer needs to get more information to determine whether the service animal will be disruptive (e.g., the employer could have the employee demonstrate the animal's behavior and current level of training).

Accommodating Employees Who Use Service Animals

Note: People use service animals for a variety of reasons, so their accommodation needs will vary. The following is only a sample of the accommodation possibilities available. Numerous other accommodation solutions may exist.

Questions to Consider:

1. What limitations is the employee who uses a service animal experiencing?
2. How do these limitations affect the employee and the employee's job performance?
3. What specific job tasks are problematic as a result of these limitations?
4. What accommodations are available to reduce or eliminate these problems? Are all possible resources being used to determine possible accommodations?
5. Has the employee who uses the service animal been consulted regarding possible accommodations?
6. Once accommodations are in place, would it be useful to meet with the employee who uses the service animal to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
7. Do supervisory personnel and employees need training regarding the use of service animals?

Accommodation Ideas:

Using a service animal at work:

- Allow the employee with a disability to bring his or her service animal to work.
- Allow the employee to take leave in order to participate in individualized service animal training.
- Provide the employee with a private/enclosed workspace.
- Provide the employee with an office space near a door and/or out of high traffic areas.
- Establish an accessible path of travel that is barrier-free.
- Allow equal access to employee break rooms, lunchrooms, rest rooms, meeting rooms, and services provided/sponsored by the employer.

Caring for a service animal at work:

- Provide a designated area where the employee can tend to the service animal's basic daily needs, e.g., eating or bodily functions.

- Allow periodic breaks so the employee can care for the service animal's basic daily needs.
- Provide a designated area the service animal can occupy until the employee's shift ends if the employee only requires the service animal to travel to and from work.
- Provide general disability awareness training on the use of service animals in the workplace.

Dealing with coworkers who are allergic to the service animal:

- Allow the employees to work in different areas of the building.
- Establish different paths of travel for each employee.
- Provide one or each of the employees with private/enclosed workspace.
- Use a portable air purifier at each workstation.
- Allow flexible scheduling so the employees do not work at the same time.
- Allow one of the employees to work at home or to move to another location.
- Develop a plan between the employees so they are not using common areas - such as the break room and restroom - at the same time.
- Allow the employees to take periodic rest breaks if needed, e.g., to take medication.
- Ask the employee who uses the service animal if (s)he is able to temporarily use other accommodations to replace the functions performed by the service animal for meetings attended by both employees.
- Arrange for alternatives to in-person communication, such as e-mail, telephone, teleconferencing, and videoconferencing.
- Ask the employee who uses a service animal if (s)he is willing to use dander care products on the animal regularly.
- Ask the employee who is allergic to the service animal if (s)he wants to, and would benefit from, wearing an allergen/nuisance mask.
- Add HEPA filters to the existing ventilation system.
- Have the work area - including carpets, cubicle walls, and window treatments - cleaned, dusted, and vacuumed regularly.

Interacting with a service animal:

- Address the person when approaching a person with a disability who is accompanied by a service animal.
- Remember that service animals are working and are not pets.
- Do not touch, pet, or feed treats to a service animal without the owner's permission.

Situations and Solutions:

A state employee with a mobility impairment uses a scooter and a service animal. The employer was concerned about how the employee would tend to the service animal's basic daily needs. JAN provided product information on a scooter with a long handle so the employee could use his scooter to go outside and tend to his service animal's "restroom" breaks.

An insurance agency employee with multiple sclerosis and anxiety requested that the employer permit her to use a service dog on the job for mobility and stress reduction. The employer agreed to allow the employee to bring her service animal to work, provided training to staff on service animals as workplace accommodations, and installed new doors that were easier for the individual to open.

A newly hired teacher with a seizure disorder used a service animal to alert her that a seizure was coming on. The school had a "no animal" policy. The school allowed the teacher to bring her service animal to work and to keep it with her in her classroom. She was also provided breaks to take the service animal outside and given the opportunity to educate coworkers about the use of service animals. The employer reported that the accommodation cost nothing and it was good for the students to see a service animal at work.

A truck driver who used a service animal requested that his dog be left in his truck during maintenance and cleaning, meetings, and the completion of paperwork. The employer purchased a dog kennel for the times when the driver had to leave his vehicle and remain in the office building for extended periods of time.

A dental office hired a receptionist with a vision impairment to work in the front office. The new employee had acquired a service animal, but did not yet have accrued vacation time that could be used for service animal training. The employer allowed the receptionist to take unpaid leave to attend service animal training.

Products:

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource (SOAR) at <http://AskJAN.org/soar> is designed to let users explore various accommodation options. Many product vendor lists are accessible through this system; however, upon request JAN provides these lists and many more that are not available on the Website. Contact JAN directly if you have specific accommodation situations, are looking for products, need vendor information, or are seeking a referral.

References

Delta Society (n.d.) *Service animal basics*. Retrieved June 15, 2011, from

<https://www.deltasociety.org/Page.aspx?pid=303>

Department of Justice (n.d.). Title III regulations. Retrieved June 15, 2011, from

http://www.ada.gov/regs2010/titleIII_2010/titleIII_2010_withbold.htm

Equal Employment Opportunity Commission. (2002). *Reasonable accommodation and undue hardship under the ADA*. Retrieved June 15, 2011, from

<http://www.eeoc.gov/policy/docs/accommodation.html>

Resources

Job Accommodation Network

West Virginia University
PO Box 6080
Morgantown, WV 26506-6080
Toll Free: (800)526-7234
TTY: (877)781-9403
Fax: (304)293-5407
jan@AskJAN.org
<http://AskJAN.org>

The Job Accommodation Network (JAN) is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities.

Office of Disability Employment Policy

200 Constitution Avenue, NW, Room S-1303
Washington, DC 20210
Toll Free: (866)633-7365
TTY: (877)889-5627
Fax: (202)693-7888
<http://www.dol.gov/odep/>

The Office of Disability Employment Policy (ODEP) is an agency within the U.S. Department of Labor. ODEP provides national leadership to increase employment opportunities for adults and youth with disabilities while striving to eliminate barriers to employment.

Animal Legal & Historical Web Center

Michigan State University College of Law
East Lansing, MI 48824-1300
Direct: (517)432-6800
Editor@animallaw.info
<http://www.animallaw.info>

The Animal Law and History Web Center is a project of Michigan State University College of Law. It first opened in August 2002. Their goals are: to provide a Web Library of legal and policy materials as relates to animals, to provide expert explanation of materials for both the lawyer and the non-lawyer, to be an education center for this material, offering courses at different levels of education with and without credit, and to provide an historical perspective about social and legal attitudes toward animals and how we got to our present perspective.

Delta Society

875 - 124th Avenue NE #101
Bellevue, 98005
Direct: (425)679-5500
Fax: (425)679-5539
info@deltasociety.org
<http://www.deltasociety.org/>

The Delta Society is the leading international resource for the human-animal bond. Delta Society has been the force to validate the important role of animals for people's health and well-being by promoting the results of research to the media and health and human services organizations.

Guide Dog Foundation for the Blind, Inc.

371 East Jericho Turnpike
Smithtown, NY 11787-2976
Toll Free: (800)548-4337
Direct: (631)930-9000
Fax: (631)361-5192
info@guidedog.org
<http://www.guidedog.org>

Since 1946, the Guide Dog Foundation for the Blind, Inc. has provided guide dogs free of charge to blind people who seek enhanced mobility and independence.

Psychiatric Service Dog Society

PO Box 754
Arlington, VA 22216
Direct: (571)216-1589
joan.esnayra@mac.com
<http://www.psychdog.org/>

The Psychiatric Service Dog Society is a 501(c)3 nonprofit organization dedicated to responsible Psychiatric Service Dog (PSD) education, advocacy, research and training facilitation. The Society provides essential information for persons disabled by severe mental illness, who wish to train a service dog to assist with the management of symptoms.

Seeing Eye, The

P.O. Box 375
Morristown, NJ 07963
Direct: (973)539-4425
Fax: (973)539-0922
info@seeingeye.org
<http://www.seeingeye.org>

The Seeing Eye, Inc., is the oldest existing dog guide school in the world. Twelve times a year, as many as 24 students at a time visit the Morristown, N.J., campus to discover the exhilarating experience of traveling with a Seeing Eye dog.

Service Animal Registry of America (SARA)

PO Box 607
Midlothian, TX 76065
Toll Free: (866)841-9139
saraorg@aol.com
<http://www.affluent.net/sara>

SARA's mission is to promote the use of service animals by the disabled; to increase public awareness of the disabled rights concerning service animals; to encourage and support positive federal, state, and local legislation involving service animals; to serve as advocates against restrictive legislation for service animals, service animals in training, service animal trainers, and mandatory certification of service animals; and to maintain a national database of service animals, service animal trainees, and therapy animals in use in the United States.

U.S. Department of Justice Disability Rights Section

Civil Rights Division Disability Rights Section
950 Pennsylvania Avenue, NW
Washington, DC 20530
Toll Free: (800)514-0301
TTY: (800)514-0383
Fax: (202)307-1197
www.usdoj.gov/crt/about/drs

The primary goal of the Disability Rights Section is to achieve equal opportunity for people with disabilities in the United States by implementing the Americans with Disabilities Act (ADA). Through its multi-faceted approach toward achieving compliance with the ADA, this Section works to make this goal a reality. The Section's enforcement, certification, regulatory, coordination, and technical assistance activities, required by the ADA, combined with an innovative mediation program and a technical assistance grant program, provide a cost-effective and dynamic approach for carrying out the ADA's mandates.

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LIMITATIONS ON TREATMENT OF PERSON WITH DEVELOPMENTAL DISABILITY

66-405. ORDER IN PROTECTIVE PROCEEDINGS.

(7) Except as otherwise provided in subsection (8) of this section, a guardian appointed under this chapter shall have no authority to refuse or withhold consent for medically necessary treatment when the effect of withholding such treatment would seriously endanger the life or health and well-being of the respondent. To withhold or attempt to withhold consent for such treatment may be cause for removal of the guardian. Except as otherwise provided in subsection (8) of this section, no health care provider or caregiver shall, based on such guardian's direction or refusal to consent to care, withhold or withdraw such treatment for a respondent. If the health care provider cannot obtain valid consent for such medically necessary treatment from the guardian, the health care provider or caregiver shall provide the medically necessary treatment as authorized by section 39-4504(1)(i), Idaho Code.

(8) A guardian appointed under this chapter may consent to withholding or withdrawing treatment other than appropriate nutrition or hydration to a respondent, and a health care provider may withhold or withdraw such treatment in reliance upon such consent, when in the treating LIP's reasonable medical judgment any of the following circumstances apply:

- (a) The attending LIP and at least one (1) other LIP certifies that the respondent is chronically and irreversibly comatose;
- (b) The treatment would merely prolong dying, would not be effective in ameliorating or correcting all of the respondent's life-threatening conditions, or would otherwise be futile in terms of the survival of the respondent; or
- (c) The treatment would be virtually futile in terms of the survival of the respondent and would be inhumane under such circumstances.

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

If adult protective services or the protection and advocacy system determines that withholding of medical treatment violates the provisions of this section, they may petition the court for an ex parte order to provide or continue the medical treatment in question. If the court finds, based on affidavits or other evidence, that there is probable cause to believe that the withholding of medical treatment in a particular case violates the provisions of this section, and that the life or health of the patient is endangered thereby, the court shall issue an ex parte order to continue or to provide the treatment until such time as the court can hear evidence from the parties involved. Petitions for court orders under this section shall be expedited by the courts and heard as soon as possible. No bond shall be required of a petitioner under this section.

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

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

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

(c) Delegate the powers granted by the order.

(11) Nothing in this section shall affect the rights of a competent patient or surrogate decision-maker to withhold or withdraw treatment pursuant to section 39-4514, Idaho Code, unless the patient is a respondent as defined in section 66-402, Idaho Code.

History:

[66-405, added 1982, ch. 59, sec. 7, p. 100; am. 1999, ch. 293, sec. 2, p. 734; am. 2005, ch. 120, sec. 8, p. 394; am. 2007, ch. 196, sec. 19, p. 594; am. 2008, ch. 74, sec. 5, p. 198; am. 2009, ch. 86, sec. 3, p. 238; am. 2012, ch. 302, sec. 15, p. 838; am. 2013, ch. 262, sec. 6, p. 645; am. 2014, ch. 164, sec. 7, p. 465; am. 2017, ch. 273, sec. 6, p. 718.]