STERILIZATION OF MINORS

Policy: Parents or legally authorized surrogates may not consent to the sterilization of a mentally incompetent person, including any minor. Only a mentally competent adult patient may provide informed consent for a medical procedure that would result in sterilization. If the patient cannot give informed consent, because the patient is either a minor or lacks mental capacity, then a court order authorization must be obtained.

This policy applies to all medical or surgical procedures that remove or alter reproductive organs in such a way to eliminate the organ's function or usefulness, where any desired or intended effect of the procedure is to render the patient incapable of reproduction, regardless of whether it is the primary purpose of the procedure.

Definitions (from Stedman's Medical Dictionary):
Sterilization: the act or process by which an individual is rendered incapable of fertilization or reproduction.
Female sterility: the inability of the female to conceive, due to inadequacy in structure or function of the genital organs.

Procedure:

1. No surgical procedure for sterilization may be scheduled or performed except in the following circumstances:
   a. A competent adult patient provides informed consent in writing for the adult patient’s own procedure; OR
   b. A court order specifically authorizing the planned surgical procedure for any adult patient who lacks mental capacity to consent, or for any minor patient, has been placed in the patient’s medical record.
   c. A minor patient who has obtained a Declaration of Emancipation should be treated as a competent adult patient, unless at the time there appears to be any doubt regarding the patient’s current mental capacity.

2. In addition, any surgical procedure for sterilization must be reviewed with and approved by all of the following:
   a. The Medical Director;
   b. The Ethics Committee; and
   c. Children’s General Counsel.

3. A petition for a court order authorizing sterilization should usually be brought by the parents or legal guardian of the patient for whom the procedure is proposed. Parents or legal guardians should consult with their own counsel in preparing and pursuing the petition.
4. In highly unusual circumstances, the parents or legal guardians of the patient may request that Children's prepare, file and pursue the petition for a court order approving the sterilization procedure. Any such request should be directed to the Medical Director, who will consult with the General Counsel and formulate a recommendation to the President or Chief Executive Officer. The ultimate decision whether Children's will prepare, file and pursue any such petition rests with the President or Chief Executive Officer, either of whom may make this decision. The decision whether to prepare, file and pursue any petition shall be documented in writing.

5. An exception to the procedures set forth above may be allowed for a surgical or medical procedure where the fact that a patient is rendered unable to reproduce is an unavoidable, unintended and undesired effect of a medically-indicated procedure that is within the standard of care for the patient's condition. Examples include a hysterectomy in the case of a true hermaphrodite, a hysterectomy to control acute hemorrhage, resection of malignant tissue, or chemotherapy or radiation treatment of cancer that causes loss of the ability to reproduce. Any exception to the procedures set forth above must be reviewed and approved by the Medical Director, in consultation with the Ethics Committee and Children's General Counsel.
Exhibit L

Special CHRMC Ethics Committee Meeting/Consultation (May, 2004)
5/5/2004 - Special CHRMC Ethics Committee Meeting/Consultation

Patient: Ashley
CHRMC

Issue of Concern:

The parents of and the physicians involved with the care of this patient have proposed aggressive intervention (both surgical and pharmacologic) to limit her linear growth and sexual development. The rationale for such is their feeling that the patient’s quality of life will be substantially improved.

Medical Facts:

Ashley [redacted] is a 6-3/4 year-old female who has static encephalopathy that has been present since birth. The etiology of such is undetermined despite extensive workup. Ashley’s specific problems include:

- profound developmental delay/mental retardation (developmental level less than 6 months?)
- global hypotonia with virtual absence of any voluntary movements
- absent coordinated swallowing
- heel cord contractures
- scoliosis
- possible reflux
- possible seizures
- premature onset of puberty

The prognosis for longterm survival, according to the physicians involved, appears to be good. The prognosis for improvement in any of the patient's primary problems is nil.

Parent Preferences:

Given the recent clinical indications that Ashley is developing precocious puberty, her parents and her physicians have developed a proposal that has three components:

1. limit her adult height
2. remove her uterus
3. remove her breasts before they develop (see attached parental proposal that was presented to the Ethics Committee)
Quality of Life:

Ashley's ability to interact with her environment appears to be limited. However, when one watches her with her parents there seems to be some positive interaction. Clearly, her quality of life is totally dependent on her parents who are her primary, and for the most part only, caretakers. Such care includes regular and constant movement/body placement, feeding, clearance of respiratory tract secretions, facilitation of bowel movements, total body hygiene, etc. Notably, the patient's total dependence on her caretakers to maintain a reasonable quality of life forms the basis for their interventional proposal.

Context:

The proposal for the aggressive interventions (described in more detail in the following section) is viewed in the context of parental motivation. The parents are intelligent, well educated, assertive and appear to be very loving and committed to provide the best care possible in their home for Ashley. Their stated goal is to maximize Ashley's quality of life. The members of the Ethics Committee present during the review of this case were all quite impressed with the interactions between Ashley and both her mother and father.

Discussion/Summary:

The Committee met with Ashley, her parents and the three involved physicians (Drs. Gunther, Cowan, O'Neal) for over an hour to hear their presentation and ask questions. It then met for another hour in closed session and considered each of the specific proposals.

1. To limit linear growth by administering high dose estrogen for approximately 18 months. The potential risk of this would be the side effects of high dose estrogen (increased potential for deep vein thrombosis, possible weight gain, possible nausea). The potential benefit of such an approach would be that Ashley's care (and her quality of life) would be facilitated by a smaller rather than a larger size, i.e. moving in/out of bed, wheelchair, car, bathtub, and changing position to avoid pressure sores, etc. The area of concern regarding this intervention is that this is not a standard of care and would in all likelihood be “new territory” in the management of profoundly retarded juvenile patients.

2. Hysterectomy. The potential risk for this approach would be anesthesia, surgery and post-operative recovery period, with the additional short term discomfort and suffering associated with such. The potential benefit would be to avoid the menstrual cycle, physical discomfort, hygienic issues, confusion and anxiety in an individual unable to understand what is going on. An additional potential
benefit would be to totally exclude the possibility of the patient being sexually assaulted and impregnated. The area of concern would be sterilization of a minor patient with mental retardation, raising both ethical and legal issues. According to a brief review of case law in Washington state there is need for a court review of this aspect of proposal.

3. Mastectomy. The potential risk of this procedure is minimal at this time with the patient's breast development being rudimentary. The potential benefit is comfort/quality of life improvement; there is a family history of large breasts with fibrous cystic disease and breast cancer. It is notable that it was pointed out that the restraint strap that holds Ashley in the wheel chair goes right across the area of her body where the breasts would be if they develop. The area of concern for this part of the proposal would be that it is clearly not the standard of care for a minor patient with developmental delay and would, like the limitation of linear growth, be "new territory" in the management of such a patient.

The discussion of these issues by the Committee was thorough, painful and occurred with considerable initial division of the members as to whether or not to support the proposal. Discussion topics included:

1. How will limiting linear growth specifically help Ashley?
2. Is there another method of inhibiting the menstrual cycle and should it be utilized to avoid subjecting Ashley to a hysterectomy?
3. How will the mastectomy improve Ashley's quality of life?
4. Who will really benefit here? The patient or her parents?

Conclusions:

After discussion of all of the above issues and more, it was the consensus of the Committee members that the potential long term benefit to Ashley herself outweighed the risks; and that the procedures/interventions would improve her quality of life, facilitate home care, and avoid institutionalization in the foreseeable future.

Parents were informed of the Committee's conclusion and were advised to seek legal advice so they could meet the Washington state case law sterilization procedures.
Exhibit M

In re Hayes, 93 Wn.2d 536, 237, (1980)
[No. 45612. En Banc. March 27, 1980.]

In the Matter of the Guardianship of
Edith Melissa Maria Hayes.

[1] Civil Rights — Mental Health — Sterilization of Incompetent — Judicial Authority. Under the grant of judicial power in Const. art. 4, § 6, superior courts have jurisdiction to entertain and act upon a petition for an order authorizing sterilization of a mentally incompetent person.

[2] Mental Health — Sterilization of Incompetent — Guardian Ad Litem — Necessity. A disinterested guardian ad litem must be appointed to represent a mentally incompetent person in a proceeding to determine whether such person should be sterilized.

[3] Mental Health — Sterilization of Incompetent — Standards — Degree of Proof. A court may authorize the sterilization of a mentally incompetent person only if it determines, after considering independent medical, psychological, and social evidence and the view of the incompetent person, in a proceeding in which the incompetent individual is represented by a guardian ad litem, that sterilization is in the person's best interest. There must be clear, cogent, and convincing evidence that the person is incapable of deciding for himself about sterilization at that time and in the foreseeable future; that contraception is needed, as determined by considering the likelihood that the person would engage in sexual activity resulting in pregnancy and the person's potential as a parent; that there exists no less drastic method of contraception or less intrusive method of sterilization; and that there is no likelihood of scientific progress in achieving a reversible sterilization procedure or a new means of treating the person's disability.

Stafford and Hicks, JJ., dissent in part by separate opinion; Rosellini, Wright, and Brachtenbach, JJ., dissent by separate opinion.

Nature of Action: A mother sought a court order authorizing sterilization of her mentally retarded daughter. Although 16 years old and capable of bearing children, the daughter functioned at the level of a 4– or 5–year–old child.

Superior Court: The Superior Court for Grant County, No. 7768, Fred Van Sickle, J., dismissed the petition on July 1, 1977.

Supreme Court: Six Justices hold that the trial court has jurisdiction over the petition for sterilization of a mentally retarded person, and the dismissal for lack of jurisdiction is reversed. Only four Justices, however, hold that the trial court should proceed with the matter prior to legislative action declaring public policy or establishing procedures.

Ries & Kenison, by Darrell E. Ries and Larry W. Larson, for appellant.

Collins & Hansen, by Howard W. Hansen and Nels A. Hansen, for respondent.

Karen Marie Thompson and Catherine C. Morrow on behalf of Legal Advocates for the Disabled and Linda Potter, Judith E. Cohn, Michael S. Lottman, and Norman S. Rosenberg on behalf of Mental Health Law Project, amici curiae.

Horowitz, J.—This appeal raises the question whether the Supreme Court for Grant County has authority to grant a petition for sterilization of a severely mentally retarded person.

Petitioner Sharon Hayes is the mother of Edith Melissa Maria Hayes, who was born severely mentally retarded on December 17, 1963. She petitioned the Superior Court for an order appointing her as the guardian of Edith’s person and specifically authorizing a sterilization procedure on Edith. The court dismissed the petition on a motion for summary judgment on the ground it had no authority to issue an order for sterilization of a retarded person. Petitioner appeals the court’s conclusion it cannot authorize sterilization of a mentally incompetent person. She does not raise the question whether the court properly denied her petition to be appointed guardian of Edith’s person.

We hold that the Superior Court has jurisdiction to entertain and act upon a request for an order authorizing sterilization of a mentally incompetent person under the
broad grant of judicial power in Const. art. 4, § 6. We further hold that, in the absence of controlling legislation, the court may grant such a petition in the rare and unusual case that sterilization is in the best interest of the retarded person. We therefore reverse the order granting summary judgment and remand for further proceedings consistent with this opinion.

Edith Hayes is severely mentally retarded as a result of a birth defect. Now 16 years old, she functions at the level of a 4- or 5-year-old. Her physical development, though, has been commensurate with her age. She is thus capable of conceiving and bearing children, while being unable at present to understand her own reproductive functions or exercise independent judgment in her relationship with males. Her mother and doctors believe she is sexually active and quite likely to become pregnant. Her parents are understandably concerned that Edith is engaging in these sexual activities. Furthermore, her parents and doctors feel the long term effects of conventional birth control methods are potentially harmful, and that sterilization is the most desirable method to ensure that Edith does not conceive an unwanted child.

Edith's parents are sensitive to her special needs and concerned about her physical and emotional health, both now and in the future. They have sought appropriate medical care and education for her, and provided her with responsible and adequate supervision. During the year or so that Edith has been capable of becoming pregnant, though, they have become frustrated, depressed and emotionally drained by the stress of seeking an effective and safe method of contraception. They believe it is impossible to supervise her activities closely enough to prevent her from becoming involved in sexual relations. Thus, with the consent of Edith's father, Sharon Hayes petitioned for an order appointing her guardian and authorizing a sterilization procedure for Edith.

I

JURISDICTION


These cases are not controlling. Their results are conclusory, as none of them demonstrates any controlling legal principle prohibiting a court of general jurisdiction from acting upon a petition for sterilization. They suggest instead a preference that the difficult decisions regarding sterilization be made by a legislative body. This is not simply a denial of jurisdiction, but an abdication of the judicial function. We are mindful that a court "cannot escape the demands of judging or of making . . . difficult appraisals." Haynes v. Washington, 373 U.S. 503, 515, 10 L. Ed. 2d 513, 83 S. Ct. 1336 (1973).

[1] Persuasive authority for the principle that courts of general jurisdiction do have jurisdiction over a petition by a parent or guardian for an order authorizing sterilization is found in the United States Supreme Court opinion in Stump v. Sparkman, 435 U.S. 349, 55 L. Ed. 2d 331, 98 S. Ct. 1099 (1978). In that case a woman sterilized pursuant to court order when she was a child later brought a civil rights action against the judge who issued the order. The question was whether the judge lacked judicial immunity for the act. The court determined the judge's conduct in entertaining and approving the petition for sterilization constituted a
judicial act, and that he had not acted in the clear absence of all jurisdiction. With regard to the jurisdiction issue, the court noted the judge was a member of a court which had broad jurisdiction at law and in equity, and which was not prohibited from considering a petition for sterilization by either statute or controlling case law. It concluded the judge had "the power to entertain and act upon the petition for sterilization" and was entitled to judicial immunity in the suit. Stump v. Sparkman, supra at 364. See generally Note, Judicial Immunity, 11 Ind. L. Rev. 489 (1978).

The courts of this state have long recognized the inherent power of the superior court "to hear and determine all matters legal and equitable in all proceedings known to the common law". (Italics ours.) In re Hudson, 13 Wn.2d 673, 697-98, 126 P.2d 765 (1942). Original jurisdiction is granted to superior courts over all cases and proceedings in which jurisdiction is not vested exclusively in some other court by Const. art. 4, § 6. Under this broad grant of jurisdiction the superior court may entertain and act upon a petition from the parent or guardian of a mentally incompetent person for a medical procedure such as sterilization. No statutory authorization is required. The rule stated in In re Hudson regarding the jurisdiction of the court over infants is equally applicable to those in need of guardianship because of severe mental retardation:

We agree . . . that the superior courts of this state are courts of general jurisdiction and have power to hear and determine all matters legal and equitable in all proceedings known to the common law, except in so far as those have been expressly denied; that the jurisdiction of a court of equity over the persons, as well as the property, of infants has long been recognized; and that the right of the state to exercise guardianship over a child does not depend on a statute asserting that power. Weber v. Doust, 84 Wash. 330, 146 Pac. 623 . . .

In re Hudson, supra at 697-98.

Nor is a statute required to empower a superior court to exercise its jurisdiction by granting a petition for sterilization. We recognize the power of the legislature, subject to the state and federal constitutions, to enact statutes regulating sterilization of mentally incompetent persons in the custody of a parent or guardian. It has not done so, however. The relevant guardianship statute, RCW 11.92, defines the duties of a guardian to care for, maintain, and provide education for an incompetent person. The statute neither provides nor prohibits sterilization procedures at a guardian's request. It does not in any event derogate from the judicial power of the court which includes the power to authorize such a procedure where it is necessary. In the absence of any limiting legislative enactment, the superior court has full power to take action to provide for the needs of a mentally incompetent person, just as it has authority to do so to protect the interests of a child. See In re Hudson, supra. We hold the superior court of the State of Washington has authority under the state constitution to entertain and act upon a petition for an order authorizing sterilization of a mentally incompetent person, and in the absence of legislation restricting the exercise of that power, the court has authority to grant such a petition.

We note that courts in at least four other states have reached the same conclusion with regard to the authority of their own courts of general jurisdiction. In In re Salminaer, 85 Misc. 2d 295, 378 N.Y.S.2d 989 (1976) the Supreme Court of the State of New York held it had power to grant a petition for sterilization under its common-law jurisdiction to act as parens patriae with respect to incompetents. Similar analysis was used by the Chancery Division of New Jersey's Superior Court in In re L.G., No. C-1917-78E (N.J. Super., July 12, 1979). The Ohio probate court found authority in the plenary power, granted to the court by statute to dispose of all matters at law and in equity which are properly before the court. In re Simpson, 180 N.E.2d 206 (Ohio P. Ct. 1962). In Ex Parte Eaton (Baltimore Cir. Ct. 1954), the Circuit Court of Baltimore, Maryland, held it could issue an order for sterilization under its general equity powers. Furthermore, the power of a state court to order sterilization without specific statutory authorization
was impliedly recognized by a federal district court in *Wyatt v. Aderholt*, 368 F. Supp. 1383 (M.D. Ala. 1974).

We therefore hold that Const. art. 4, § 6 gives the superior courts of this state the jurisdiction to entertain and act upon a request for an order authorizing sterilization of a mentally incompetent person.

II

STANDARDS FOR STERILIZATION

Our conclusion that superior courts have the power to grant a petition for sterilization does not mean that power must be exercised. Sterilization touches upon the individual's right of privacy and the fundamental right to procreate. *North Carolina Ass'n for Retarded Children v. North Carolina*, 420 F. Supp. 451, 458 (M.D.N.C. 1976), citing *Roe v. Wade*, 410 U.S. 113, 35 L. Ed. 2d 147, 93 S. Ct. 705 (1973); *Eisenstadt v. Baird*, 405 U.S. 438, 31 L. Ed. 2d 349, 92 S. Ct. 1029, (1972); *Skinner v. Oklahoma*, 316 U.S. 535, 86 L. Ed. 1655, 62 S. Ct. 1110 (1942). See also P. Friedman, *The Rights of Mentally Retarded Persons* 117–19 (1976) (hereinafter cited as *Mentally Retarded Persons*). It is an unalterable procedure with serious effects on the lives of the mentally retarded person and those upon whom he or she may depend. Therefore, it should be undertaken only after careful consideration of all relevant factors. We conclude this opinion with a set of guidelines setting out the questions which must be asked and answered before an order authorizing sterilization of a mentally incompetent person could be issued. First, however, the considerations which are important to this determination can be best illuminated by discussing briefly the historical context from which they arise.

Sterilization of the mentally ill, mentally retarded, criminals, and sufferers from certain debilitating diseases became popular in this country in the early 20th century. The theory of "eugenic sterilization" was that the above named traits and diseases, widely believed at that time to be hereditary, could be eliminated to the benefit of all society by simply preventing procreation.

More than 20 states passed statutes authorizing eugenic sterilizations. Washington passed a punitive sterilization law aimed at habitual criminals and certain sex offenders in 1909. The law exists today as RCW 9.92.100. Another statute, also enacted early in the century, denied certain persons, including the mentally retarded, the right to marry unless it is established that procreation by the couple is impossible. RCW 26.04.030, repealed by Laws of 1979, 1st Ex. Sess., ch. 128, § 4. While this statute did not authorize sterilizations, it was clearly based on eugenic principles.

In 1921 the Washington legislature enacted a law providing for sterilization of certain mentally retarded, mentally ill and habitually criminal persons restrained in a state institution. Laws of 1921, ch. 53, p. 162. This statute was held unconstitutional because of its failure to provide adequate procedural safeguards in *In re Hendrickson*, 12 Wn.2d 600, 123 P.2d 322 (1942).

The United States Supreme Court upheld the constitutionality of a eugenic sterilization law which provided adequate procedural safeguards, however, in *Buck v. Bell*, 274 U.S. 200, 71 L. Ed. 1000, 47 S. Ct. 584 (1927). Since that time it has generally been believed that eugenic sterilization statutes are constitutional although, as noted above, more recent Supreme Court decisions suggest the importance of respecting the individual's constitutional rights of privacy and procreation. See generally S. Brakel & R. Rock, *American Bar Foundation Study, the Mentally Disabled and the Law* (rev. ed. 1971) (hereinafter referred to as *A.B. Foundation Study*) and J. Robitscher, *Eugenic Sterilization* (1973) (hereinafter referred to as *Eugenic Sterilization*).

More recently scientific evidence has demonstrated little or no relationship between genetic inheritance and such conditions as mental retardation, criminal behavior, and diseases such as epilepsy. Geneticists have discovered, for example, that some forms of mental retardation appear to
have no hereditary component at all, while in some others
the element of heredity is only one of a number of factors
which may contribute to the condition. See A.B. Foundation
Study, supra at 211; Eugenic Sterilization, supra at
113–16; Mentally Retarded Persons, supra at 115–17. In
short, the theoretical foundation for eugenic sterilization as
a method of improving society has been disproved.

At the same time other previously unchallenged assump-
tions about mentally retarded persons have been shown to
be unreliable. It has been found, for example, that far from
being an insignificant event for the retarded person, steri-
лизation can have long-lasting detrimental emotional effects.
Eugenic Sterilization, supra at 21–22; Mentally Retarded
Persons, supra at 116. Furthermore, while retarded per-
sons, especially children, are often highly susceptible, there
is evidence they are also capable of learning and adhering
to strict rules of social behavior. Eugenic Sterilization,
supra at 19. Many retarded persons are capable of having
normal children and being good parents. Eugenic Steriliza-
tion, supra at 20; Mentally Retarded Persons, supra at
116.

[2] Of great significance for the problem faced here is
the fact that, unlike the situation of a normal and necessary
medical procedure, in the question of sterilization the
interests of the parents of a retarded person cannot be
presumed to be identical to those of the child. The problem of
parental consent to sterilization is of great concern to pro-
fessionals in the field of mental health, and the over-
whelming weight of opinion of those who have studied the
problem appears to be that consent of a parent or guardian
is a questionable or inadequate basis for sterilization. See
A.B. Foundation Study, supra at 216; Mentally Retarded
Persons, supra at 121; 2 P.L.I. Mental Health Project, at
1024 (1973); President's Committee on Mental Retardation,
The Mentally Retarded Citizen and the Law, at 101–05
(1976); Eugenic Sterilization, supra at 121; Comment,
Sterilization, Retardation and Parental Authority, 1978
B.Y.L. Rev. 380 (1978); Murdock, Sterilization of the

*Retarded: A Problem or a Solution?, 62 Cal. L. Rev. 917,
932–34 (1974). See also North Carolina Ass'n for Retarded
(M.D.N.C. 1976). It is thus clear that in any proceedings to
determine whether an order for sterilization should issue,
the retarded person must be represented, as here, by a dis-
interested guardian ad litem.

[3] Despite all that has been said thus far, in the rare
case sterilization may indeed be in the best interests of the
retarded person. This was recognized in North Carolina
Ass'n for Retarded Children v. North Carolina, supra at
454–55. However, the court must exercise care to protect
the individual's right of privacy, and thereby not unneces-
sarily invade that right. Substantial medical evidence must
be adduced, and the burden on the proponent of steriliza-
tion will be to show by clear, cogent and convincing evi-
ence that such a procedure is in the best interest of the
retarded person.

Among the factors to be considered are the age and edu-
cability of the individual. For example, a child in her early
 teens may be incapable at present of understanding the
consequences of sexual activity, or exercising judgment in
relations with the opposite sex, but may also have the
potential to develop the required understanding and judg-
ment through continued education and developmental
programs.

A related consideration is the potential of the individual
as a parent. As noted above, many retarded persons are
able of becoming good parents, and in only a fraction of
cases is it likely that offspring would inherit a genetic form
of mental retardation that would make parenting more
difficult.

Another group of relevant factors involves the degree to
which sterilization is medically indicated as the last and
best resort for the individual. Can it be shown by clear,
cogent and convincing evidence, for example, that other
methods of birth control are inapplicable or unworkable?
In considering these factors, several courts have developed sterilization guidelines. See, e.g., North Carolina Ass'n for Retarded Citizens, supra at 456-57; Wyatt v. Aderholt, supra at 1384-86; In re L.G., supra at 34-35. With the assistance of the brief of amicus Mental Health Law Project, a careful review of these considerations allows us to provide the superior court with standards to be followed in exercising its jurisdiction to issue an order authorizing sterilization of a mentally incompetent individual.

The decision can only be made in a superior court proceeding in which (1) the incompetent individual is represented by a disinterested guardian ad litem, (2) the court has received independent advice based upon a comprehensive medical, psychological, and social evaluation of the individual, and (3) to the greatest extent possible, the court has elicited and taken into account the view of the incompetent individual.

Within this framework, the judge must first find by clear, cogent and convincing evidence that the individual is (1) incapable of making his or her own decision about sterilization, and (2) unlikely to develop sufficiently to make an informed judgment about sterilization in the foreseeable future.

Next, it must be proved by clear, cogent and convincing evidence that there is a need for contraception. The judge must find that the individual is (1) physically capable of procreation, and (2) likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy, and must find in addition that (3) the nature and extent of the individual's disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders him or her permanently incapable of caring for a child, even with reasonable assistance.

Finally, there must be no alternatives to sterilization. The judge must find that by clear, cogent and convincing evidence (1) all less drastic contraceptive methods, including supervision, education and training, have been proved unworkable or inapplicable, and (2) the proposed method of sterilization entails the least invasion of the body of the individual. In addition, it must be shown by clear, cogent and convincing evidence that (3) the current state of scientific and medical knowledge does not suggest either (a) that a reversible sterilization procedure or other less drastic contraceptive method will shortly be available, or (b) that science is on the threshold of an advance in the treatment of the individual's disability.

There is a heavy presumption against sterilization of an individual incapable of informed consent that must be overcome by the person or entity requesting sterilization. This burden will be even harder to overcome in the case of a minor incompetent, whose youth may make it difficult or impossible to prove by clear, cogent and convincing evidence that he or she will never be capable of making an informed judgment about sterilization or of caring for a child.

Review of the facts in this case in light of these standards makes it clear that the burden has not yet been met. It cannot be said that Edith Hayes will be unable to understand sexual activity or control her behavior in the future. The medical testimony and report of the mental health board are not detailed enough to provide clear, cogent and convincing evidence in this regard. Edith's youth is of particular concern, since she has many years of education before her. Furthermore, although there is evidence that some methods of birth control have already been tried, there is insufficient proof that no conventional form of contraception is a reasonable and medically acceptable alternative to sterilization. Nor is there any evidence such a procedure would not have detrimental effects on Edith's future emotional or physical health. Finally, there is no evidence that a pregnancy would be physically or emotionally hazardous to Edith, and insufficient evidence that she would never be capable of being a good parent.

Additional fact finding at the trial level will help the superior court judge answer the questions set out in this
opinion. Therefore, the case is reversed and remanded for further proceedings consistent with this opinion.

Utter, C.J., and Dolliver and Williams, JJ., concur.

Stafford, J. (concurring specially in part in the majority and dissenting in part)—I have studied the majority and dissenting opinions with care. Both express great concern for basic personal rights and the possible impact of social policy upon those rights. Yet, in resolving those complicated, and often conflicting, issues in terms of constitutional jurisdiction, the majority and dissent are in fundamental opposition. The majority declares that constitutional jurisdiction over the person and subject matter clearly gives the judiciary power to determine the ultimate conflict. The dissent asserts with equal fervor that no jurisdiction exists, constitutional or otherwise, to resolve an issue of public policy which strikes so near the underpinnings of the right of privacy. My view of the appropriate resolution lies between the two competing theories, although it is more closely allied with the majority.

I agree with the majority that the judiciary has constitutional jurisdiction over both the subject matter and the persons involved. Having jurisdiction the courts possess inherent power to define the limits of the conflict between personal rights and the asserted needs of society and thus the power to resolve the instant dispute. The majority has proceeded into this thicket with caution. While declaring the power of the judiciary to act, it has imposed upon those who stress the social need for sterilization a strong burden of proof as a condition precedent to any implementation of the claimed need. By so doing, the majority has recognized the necessity of protecting the fundamental personal rights involved.

Nevertheless, despite the cautious approach employed, I am compelled to depart from the majority. I acknowledge existence of the judicial power to act. Possession of such power, however, neither requires that it be exercised nor necessarily supports the wisdom of its exercise under all circumstances.

In this case we are concerned with the permanent and irreversible loss of a fundamental personal right. Those who seek to invade this right do so in the name of "social need", "social good" and even "personal well-being". Society, doubtless well intentioned, desires to "do what is best" for the person here involved. In my view, however, there are not only deeply seated medical, sociological, personal and legal issues, but a fundamental issue of public policy involved. What power, then, should society have in this regard; what personal rights should be protected from society; to what extent should they be protected; and in what manner?

It seems to me that having clearly declared the judiciary's power to act, wisdom dictates we should defer articulation of this complex public policy to the legislature. Such deferral, done with a clear declaration of judicial power, is not an abdication of that power. Rather, it is a recognition that the declared power can be rationally coupled with a conscious choice not to exercise it.

There will be sufficient time, after a legislative declaration of public policy, for this court to determine whether the declaration and implementation of that policy has been accomplished in a constitutional manner. There will be a sufficient opportunity, for example, for us to review and properly decide the most basic question of all—whether compulsory sterilization of mentally retarded persons should or should not be permitted and if so under what limitations, if any. We have not faced this most basic issue and have been unable to do so because of the limited nature of the briefs and limited facts in this case. By deferring the exercise of our power and permitting the legislature to declare the public policy, we will be able to meet these problems in a more acceptable and knowledgeable manner.

Since, contrary to my views, the judiciary plans to exercise its power to act in cases of this nature, it should do so
only under strict protective standards. Most of the standards enunciated by the majority fulfill this objective.

Without question those who seek intervention of the judiciary on "behalf" of an alleged mentally incompetent person usually will do so with the best of intentions. If the judiciary is willing to furnish the means of resolving such a critical issue, it should not on the one hand make the forum available and on the other hand make the burden of proof so impossible of accomplishment that the forum cannot be used. Unfortunately, the final standard proposed by the majority does just that.

The moving party is required to prove by clear, cogent and convincing evidence that "(3) the current state of scientific and medical knowledge does not suggest (a) that a reversible sterilization procedure or other less drastic contraceptive method will shortly be available, or (b) that science is on the threshold of an advance in the treatment of the individual's disability." First, the standard requires the moving party to prove a negative. Second, it involves the judiciary in a questionable contest at three levels: (a) whether the movant has done sufficient research to establish that no medical breakthrough is possible in the foreseeable future; (b) whether a medical procedure possible in the next few years will become an actuality; and (c) whether the alleged mentally incompetent person will be able to take advantage of the nebulous scientific advance for physical or emotional reasons.

It is too much to ask the moving party, the alleged mentally incompetent person or the judiciary to litigate such nebulous eventualities of science.

HICKS, J., concurs with STAFFORD, J.

ROSELLINI, J. (dissenting)—In the exercise of the police power, the legislature has provided for sterilization of certain criminals, evidently upon the mistaken belief that the tendencies exhibited by such criminals are inheritable
to order sterilization of incompetents. In an annotation entitled *Jurisdiction of court to permit sterilization of mentally defective person in absence of specific statutory authority*, 74 A.L.R.3d 1210, 1213 (1976), Thomas R. Trenkner says:

Rejecting contentions that the jurisdiction to permit such sterilizations was impliedly conferred by general statutes empowering the courts to act on the behalf of infants, mental defectives, and other incompetent persons, or by statutes investing courts with general equitable powers, these courts seem to have generally taken the view, explicitly stated in one case, that an order for the compulsory sterilization of a mental defective, whatever may be the merits of the particular case, irreversibly denies to that human being the fundamental right to bear or beget children and thus is too awesome a power to be inferred from general statutory provisions, but rather should only be conferred by specific statutory authority which provides guidelines and adequate legal safeguards determined by the people's elected representatives to be necessary after full consideration of the constitutional rights of the individual and the general welfare of the people.

(Footnotes omitted.) The public policy of the State of Washington supports this view.

The legislature at one time provided for sterilization of certain mentally deficient persons. Laws of 1921, ch. 53, p. 162. In *In re Hendrickson*, 12 Wn.2d 600, 123 P.2d 322 (1942), this court, while recognizing that the enactment of a sterilization statute was within the police power of the legislature, held the act unconstitutional because of procedural defects. Since that time the legislature has not seen fit to enact another law authorizing such sterilizations, even though it has provided for sterilization of certain other types of individuals. This means that the legislature has not seen fit to vest the judiciary with the jurisdiction to order sterilization. The lack of legislative action indicates that sterilization of mentally deficient persons has not found sufficient public support to convince the legislative body of its efficacy.

Obviously, since such legislation lies in the sphere of the police power, it is not within the inherent power of the courts, and the legislature, until today, had every right to assume that the courts would not presume to write their own law upon the subject.

The majority apparently assumes that sterilization is a matter of indifference to the person upon whom it is performed, provided, of course, he is in fact retarded. Upon this subject, Kindred in *Sixty Years of Compulsory Eugenic Sterilization: "Three Generations of Imbeciles" and the Constitution of the United States*, 43 Chi.−Kent L. Rev. 123, 139−40 (1966), says:

The third basic principle of CES [compulsory eugenic sterilization] is that sterilization is not usually felt to be a detriment by the defective person. Mr. Justice Holmes expressed this belief when he wrote that the loss of reproductive power is "...often not felt to be [a sacrifice] ... by those concerned." This may be true in the case of many imbeciles, idiots and persons prone to sexual perversion. But it can hardly be generalized of those suffering from feeblemindedness and epilepsy. One recent study indicated that many mental defectives who were forcibly sterilized by the state of California feel resentment. Others are aware that eugenic sterilization is contrary to the teaching of their religion. Some women who are capable of caring for the children of others, but have been forced to undergo CES, can only be described as bitter. The state has precluded their becoming mothers on the basis of "...a knowledge of the laws of heredity far beyond the reaches yet attained by humble scientists."

Any analysis of CES must ultimately reach this fundamental question: is the basis for this state action so apparent and reasonable that the legislature can authorize a substantial intrusion into the body of a human being? Mr. Justice Douglas has stated the seriousness of the answer to that question:

"...We are dealing here with legislation which involves one of the basic civil rights of man. Marriage and procreation are fundamental to the existence and survival of the race. There is no redemption for the individual
whom the law touches . . . he is forever deprived of a basic liberty.

(Footnotes omitted.)

The majority's reliance on In re Hudson, 13 Wn.2d 673, 126 P.2d 765 (1942) is misplaced. In that case, the Superior Court had ordered the amputation of a child's enormously enlarged arm. In a much criticized decision, this court reversed, finding the lower court lacked jurisdiction because the parents were not shown to have neglected the child within the meaning of the statute giving the courts power to take custody of dependent children. This decision was reached in spite of the fact that it was established by competent medical testimony that the operation was imperative for the child's physical and mental health.

Thus, what this court had to say in that case about the powers of the Superior Court under the then juvenile court act (Rem. Rev. Stat. § 1987) was dictum. However, I have no quarrel with it, since it merely recognized the court's power to order medical care for a dependent child. That is not the question here. This action was not brought under that statute, and had it been, the question before us would be, Did the legislature, when it authorized the court to make "any order, which in the judgment of the court, would promote the child's health and welfare" (Rem. Rev. Stat. § 1987–10), intend to give it power to order sterilization? I rather doubt that even the majority here would be inclined to give the language such a liberal interpretation. Observing the recital of relevant facts in the majority opinion, it would appear that the focal point of concern is the welfare of the parents more than the health and welfare of the child. Their welfare may indeed be a legitimate social concern, but it is for the legislature to determine whether the public interest warrants the protection of parents from the anxieties, stresses and responsibilities thrust upon them in those circumstances, as well as whether the adverse effect of pregnancies on retarded or mentally deficient children is a problem which warrants a court intervention.

An annotation at 74 A.L.R.3d 1224 (1976) reveals that to date no court has held that a parent has the power to order sterilization of his child, whether a minor or adult.


In considering the facts at hand, it should be first noted that we are not dealing with a legislative enactment permitting sterilizations without consent where certain conditions exist.

Secondly, the facts do not bring the case within the framework of those decisions holding either that the parents may consent on behalf of the child to medical services necessary for the child, or where the state may intervene over the parents' wishes to rescue the child from parental neglect or to save its life.

Permanent sterilization as here proposed is a different matter. Its desirability emanates not from any life saving necessities. Rather, its sole purpose is to prevent the capability of fathering children.

We believe the common law does not invest parents with such power over their children even though they sincerely believe the child's adulthood would benefit therefrom. This result has been reached most recently in In Interest of M.K.R. (Mo. 1974), 515 S.W.2d 467, and In re Kemp's Estate (1974) 43 Cal. App. 3d 758, 118 Cal. Rptr. 64, where the courts of Missouri and California held that their respective juvenile statutes making general provision for the welfare of children were insufficient to confer jurisdiction to authorize the sterilization of retarded girls in the absence of specific sterilization legislation.

(Footnotes and citations omitted.)

The United States Supreme Court has not held that a state court has inherent power to order sterilization. In Stump v. Sparkman, 435 U.S. 349, 55 L. Ed. 2d 331, 98 S. Ct. 1099 (1978), cited by the majority, the issue was whether a judge who had ordered a minor girl sterilized was
immune from liability to that girl when she reached majority, married, and discovered the author of her inability to have children. The court held that judges of the courts of superior or general jurisdiction are not liable in a civil action for their judicial acts, even when such acts are in excess of their jurisdiction and are alleged to have been done maliciously or corruptly and even though grave procedural errors occur.

The Supreme Court majority was obviously intent upon protecting the judge's immunity. The opinion certainly does not stand as an endorsement of judicially ordered sterilizations but rather as an uncompromising assertion of such immunity. I would say that it also stands as an ominous warning of how easily the asserted power to order sterilization can be mistakenly exercised.

In 1922, a great number of states adopted sterilization laws based upon the eugenic theory that human defectives could be eliminated and this would result in the improvement of the human race. The fallacy of this assumption has been demonstrated by geneticists. See Kindregan, Sixty Years of Compulsory Eugenic Sterilization: "Three Generations of Imbeciles" and the Constitution of the United States, 43 Chi.-Kent L. Rev. 123 (1966). According to his article, the overwhelming weight of scientific opinion is that defects such as retardation are not demonstrably inheritable in the case of an individual defective person. He further points out that 89 percent of all feebleminded children are born to normal parents.

The majority assumes that it is established that sterilization may be beneficial to society. And yet scientific studies cast grave doubts upon the correctness of this assumption. In a Note, Eugenic Sterilization—A Scientific Analysis, 46 Denver L.J. 631, 633–34 (1969), the author says:

"[T]he fact that some sterilizations continue to be performed and that, in any event, the threat remains of possible sterilization being imposed, even though there is questionable scientific value in such procedures, makes this a topic of continuing timeliness and interest.

Numerous legal, medical, and sociological reviews have been published on the subject, most of them unfavorable in their appraisal. The basic criticisms have been that eugenic sterilization does not accomplish its stated objective of "human betterment," and, at the same time, it interferes with important freedoms either expressly guaranteed by the United States Constitution or brought within its ambit by judicial construction.

(Footnotes omitted.)

My great concern is that the courts do not become "an imperial judiciary," a phrase coined, I believe, by Nathan Glaser. In his book Power, written late in his career, Adolph Berle spoke of the United States Supreme Court as a benevolent dictatorship. And Phillip Kurland has often traced the Supreme Court's wandering in the political thicket with no compass for a guide, save its own subjective fancies.

The rule of law is not well served by handing unrestricted policy-making power to a shifting majority of as few as five whose judgment, as Justice Jackson would say, is not final because it is infallible, but infallible because it is final.

I would affirm the judgment of dismissal.

WRIGHT and BRACHTENBACH, JJ., concur with ROSELLINI, J.

[No. 46104. En Banc. March 27, 1980.]


[1] Contracts — Quasi Contract — Lost Profits — Quantum Meruit. A quasi contract is a contract implied in law and arises out of an implied duty of the parties rather than an agreement or meeting of the minds. When the remedy of quantum meruit is applied to
Exhibit N


A review of the record demonstrates that the Board did a complete and thorough review of the project prior to issuing the final MDNS and conditional use permit. An environmental checklist was submitted as required by WAC 197-11-315(2). A DNS was issued March 8, 1988, and mailed to 14 agencies. Comments on the DNS were received from several of those agencies and based on those comments the zoning adjuster withdrew the DNS on April 14, 1988. Mr. Loshbaugh, responding to the environmental concerns which had been raised, and the Spokane Planning Department, pursuant to WAC 197-11-335, sought additional information from various agencies. Significantly, no agency recommended an EIS be required. On July 21, 1988, an MDNS was issued pursuant to WAC 197-11-350. It set forth 10 mitigating measures. On September 14, 1988, the zoning adjuster held a public hearing and issued a summary decision on October 10, 1988, denying the conditional use permit. This determination was appealed and the Board held two public hearings on that appeal, reversed the zoning adjuster, and granted the permits. The record of those hearings further demonstrates an examination of SEPA policies and environmental concerns. The Board's decision not to require an EIS is not clearly erroneous.

Reversed and remanded for entry of judgment affirming the Board's action.

GREEN, C.J., and THOMPSON, J., concur.

In the Matter of the Guardianship of K.M.

1 Guardians — Mental Health — Guardian ad Litem — Duty — Scope. The guardian ad litem for a mentally incompetent person is required to act for the benefit of that person as an advocate; the guardian ad litem must actively protect the incompetent's interests by assuming an adversary posture in proceedings affecting the incompetent person's fundamental rights.

2 Guardians — Mental Health — Guardian ad Litem — Substantial Rights — Waiver. The guardian ad litem for a mentally incompetent person is prohibited from waiving any substantial rights of that person.

3 Guardians — Mental Health — Guardian ad Litem — Duty — Sterilization. A sterilization procedure cannot be authorized for a mentally incompetent person unless that person's guardian ad litem or independent counsel has assumed an adversary role to ensure that the proceedings are conducted in an adversary setting in which the appropriate level of proof necessary to justify the procedure is presented. The guardian ad litem or counsel must also ensure that none of the person's substantial rights are waived.

4 Constitutional Law — Right to Privacy — Interests Protected — Procreation — Forced Sterilization. A person's right to procreate is at the core of the constitutionally protected right to privacy. The power to sterilize thus affects a basic liberty interest.
[5] Guardians — Mental Health — Guardian ad Litem — Duty — Failure To Perform — Independent Counsel. When fundamental rights of a mentally incompetent person are at issue, the trial court must appoint independent counsel for the incompetent person if it becomes apparent to the court that the guardian ad litem is not providing a thorough, adversary exploration of the issues.

**Nature of Action:** The parents of an incompetent minor petitioned for appointment as guardians and for permission to have the minor sterilized.

**Superior Court:** The Superior Court for Whatcom County, No. 89-4-00252-7, Byron L. Swedberg, J., on March 13, 1990, granted the petition but stayed the sterilization authorization pending appellate review.

**Court of Appeals:** Holding that the failure of the minor’s guardian ad litem to advocate the minor’s interests required representation of the minor by independent counsel, the court reverses that portion of the order granting permission for the sterilization and remands for further proceedings.

*Michael B. Bobbink, Patricia S. Woodall and Shepherd, Abbott & Woodall, for appellant.*

*Deborra E. Garrett and Raas, Johnsen, Garrett & Stuen, P.S., for respondent.*

**Baker, J.** — This case requires us to determine whether the trial court erred in failing to appoint counsel to represent a minor incompetent at a hearing on a petition seeking an order authorizing the guardian to consent to the minor’s sterilization.

The parents of K.M., who was 15 years old at the time of trial, petitioned through counsel to be appointed guardians of the person and estate of K.M., and to be authorized to consent to her sterilization. The trial court appointed a guardian ad litem to represent the best interests of K.M., pursuant to former RCW 11.88.090 (amended 1990). The guardian ad litem appointed was an attorney. There were no appearances by any adversarial party.

Prior to trial, the guardian ad litem submitted a report recommending that no counsel be appointed to represent K.M. and that the petitioners’ request for authorization to consent to sterilization be granted.

At the time of the hearing, the trial court asked the guardian ad litem to “act as an independent examiner of any live witnesses that occur”. The court then asked the guardian ad litem to clarify the conclusion in her report that the sterilization authorization request was “responsible”. The guardian ad litem responded that she believed K.M. would be at risk emotionally were she to get pregnant and thus her recommendation was based on the best interests of K.M.³

The evidence indicated that K.M.’s diagnosis is static encephalopathy with developmental or congenital aphasia, a nonprogressive condition that hampers her ability to decipher and express speech. Since the damage occurred at or around the time of birth, there was no preservation of other forms of communication such as writing. Her IQ is 40; she functions at the mental age of a 6- to 7-year-old. K.M.’s independent functioning in various daily activities is severely limited.

K.M.’s mother testified that K.M.’s compliance and naivety cause her concern that K.M. may engage in sexual activity without the ability to make judgments regarding the consequences. K.M. currently takes birth control pills, but she needs daily monitoring. The guardian ad litem did not cross-examine the mother.

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³This case was tried prior to the effective date of the 1990 amendments to RCW 11.88, which replaced the term “incapacitated” with “incapacitated persons. See RCW 11.88.010(1).

³The affidavit of guardian ad litem, appended to respondents’ brief, which belatedly attempts further to justify her conclusions, is not properly before this court. See State v. Hughes, 106 Wn.2d 176, 206, 721 P.2d 902 (1986) (appellate record is limited to verbatim report, clerk’s papers and exhibits); RAP 9.1.
Dr. Braun, K.M.'s treating neurologist, testified that K.M. would never be capable of exercising responsible judgment in sexual and reproductive matters or in caring for a child. In his experience, pregnancy of a mentally retarded patient involves marked negative psychological impact on the patient. The guardian ad litem did not cross-examine Dr. Braun.

A counselor who met with K.M. regarding reproductive issues testified that K.M. expressed a desire not to have children because she felt she could not care for them. On cross examination by the guardian ad litem, the counselor testified that she did not know whether K.M. was parroting her parents' views or expressing her own. Although K.M. testified that she understood if she were sterilized she could not have a child, her testimony was ambiguous as to whether she understood the procedure was irreversible.

Dr. Robert Watson, a child and adolescent psychiatrist, testified regarding the negative emotional repercussions of a pregnancy on a person with K.M.'s level of impairment. The guardian ad litem was not present during Dr. Watson's testimony; thus, he was not cross-examined.

The trial court held the evidence was clear, cogent and convincing that it was in the best interests of K.M. that she be sterilized. Her guardians were given authority to consent to the sterilization. However, the trial court withheld that authority pending the appointment of an attorney for K.M. to evaluate the possibility of an appeal and pending any resulting appellate review.

RIGHT TO COUNSEL

K.M. contends she was denied her right to counsel at trial since the guardian ad litem comported herself in a nonadversarial manner and waived a number of K.M.'s substantial rights. She alleges the guardian ad litem acted improperly by recommending against the appointment of independent counsel, waiving K.M.'s right to be present during portions of the trial, failing to be present herself during portions of the trial, failing to object to absence of notice to K.M., and failing to mail K.M. a copy of her report as required by former RCW 11.88.090(3)(b) (amended 1990).

Former RCW 11.88.045(1) (amended 1990) provided that alleged incompetents are entitled to independent legal counsel and that when, in the opinion of the court, the rights and interests of an alleged or adjudicated incompetent or disabled person cannot otherwise be adequately protected and represented, the court on its own motion shall appoint an attorney at any time to represent such person.42]

Former RCW 11.88.090(3)(a) (amended 1990) provided that the guardian ad litem had a duty to meet with the alleged incompetent person and explain various legal rights, including the right to independent legal counsel and the right to be present in court at the hearing on the petition. The guardian ad litem is further required to file a written report containing, among other things, a recommendation to the court "as to whether or not counsel should be appointed to represent the alleged incompetent or disabled person, and the reasons for such recommendation." Former RCW 11.88.090(3)(b) (amended 1990). A copy of the report containing the recommendation is to be provided to the alleged incompetent.

No Washington case has explored the nature of the role of the guardian ad litem upon a petition by a parent for authorization to sterilize a minor child. The extent of our State's law on the subject of sterilization of a minor is contained in the case of In re Hayes, 93 Wn.2d 228, 608 P.2d 635 (1980), in which the nature of the guardian ad litem's role was not directly at issue.

[1, 2] The role of the guardian ad litem has been explored in other contexts, however. For example, in In re Quesnell, 83 Wn.2d 224, 517 P.2d 568 (1973), a mental illness civil commitment proceeding, the court held that the guardian ad litem is appointed for the benefit of and to protect the rights and best interests of the alleged incom-

The current version of RCW 11.88.045 has retained substantively similar language.
petent to whom he is assigned. For these purposes, it is essential that he act as an advocate in behalf of the accused.

(Citations omitted.) *Quesnell*, 83 Wn.2d at 235-36. The court held that it is the duty of the guardian ad litem to submit to the court all relevant defenses or legal claims the client may have, investigate actively any charges, consult meaningfully with the client, and explain the legal consequences of the proceedings. *Quesnell*, 83 Wn.2d at 236-38. If these affirmative efforts to provide protection for the fundamental rights of the alleged incompetent are not observed,

the appointment of the guardian ad litem can become a "mere formality" and a meaningless gesture. The nonadversary guardian ad litem necessarily does not afford realization of constitutional and statutory guarantees in regard to the assistance of counsel.

(Citation omitted.) *Quesnell*, 83 Wn.2d at 236-37.

The *Quesnell* court went on to state that it was of utmost importance, consistent with the guardian ad litem's duty to actively protect the rights of the client, that the guardian ad litem be prohibited from waiving any substantial right of the client. The rationale for this rule, the *Quesnell* court explained, was stated in *Graham v. Graham*, 40 Wn.2d 64, 240 P.2d 564 (1952), a case in which the trial court sought to appoint a guardian ad litem to represent a party defendant. There, the court explained:

There is something fundamental in the matter of a litigant being able to use his personal judgment and intelligence in connection with a lawsuit affecting him, and in not having a guardian's judgment and intelligence substituted relative to the litigation affecting the alleged incompetent.

*Graham*, 40 Wn.2d at 67. This prohibition against waiving any substantial rights of the client exists even if the appointment of the guardian ad litem is made after a hearing and determination of incompetency. See *Quesnell*, 83 Wn.2d at 238 (quoting *In re Houts*, 7 Wn. App. 476, 482, 499 P.2d 1276 (1972)).

[3] *In re Moe*, 385 Mass. 555, 432 N.E.2d 712 (1982) discussed the role of the guardian ad litem upon a guardian's petition for an order authorizing sterilization. The court held that the guardian ad litem was charged with the responsibility of zealously representing the ward, and must meet with the ward, present proof, cross-examine witnesses, and present all reasonable arguments in favor of the court's denial of the petition, so that all viewpoints will be aggressively pursued and examined. "This adversary posture will ensure that both sides of each issue which the court must consider are thoroughly aired before findings are made and a decision rendered." *Moe*, at 567; accord, *In re C.D.M.*, 627 P.2d 607, 612 (Alaska 1981). Similarly, our Supreme Court in *Hayes* held that in the question of sterilization the parents' interests cannot be presumed to be identical to the child's. *Hayes*, 93 Wn.2d at 236. "It is thus clear that in any proceedings to determine whether an order for sterilization should issue, the retarded person must be represented, as here, by a disinterested guardian ad litem." *Hayes*, 93 Wn.2d at 237.

The guardian ad litem in this case did not assume an adversary posture. Following the submission of her report supporting the petition, the guardian ad litem demonstrated in a number of ways that she regarded her role as nonadversarial. For example, she was not present during the testimony of Dr. Watson, and conducted no cross examination of Dr. Braun or K.M.'s mother.

Furthermore, without objection or comment by the guardian ad litem, the trial court granted petitioners' motion that K.M.'s presence be waived for the second half of the trial, which included the testimony of Drs. Watson and Braun. Waiver of K.M.'s right to be present at the hearing, absent special authorization by K.M., should not have been permitted. See *Quesnell*, 83 Wn.2d at 238-39.

[4] We are mindful of the gravity and finality of an authorization to sterilize. Justice William O. Douglas stated that the right to procreate is "fundamental to the
very existence and survival of the race. The power to sterilize, if exercised, may have subtle, far-reaching and devastating effects. . . . There is no redemption for the individual whom the law touches. . . . He is forever deprived of a basic liberty." Skinner v. Oklahoma ex rel. Williamson, 316 U.S. 535, 541, 86 L. Ed. 1655, 62 S. Ct. 1110, 1113 (1942), cited in Hayes, 93 Wn.2d at 234. The decision whether or not to bear a child is at the very heart of the constitutionally protected right to privacy. See Carey v. Population Servs. Int'l, 431 U.S. 678, 684-85, 52 L. Ed. 2d 675, 97 S. Ct. 2010, 2016 (1977).

[5] Given the fundamental right at issue here and the lack of adversarial testing of the relevant considerations to be weighed, we hold that the trial court erred by failing to appoint independent counsel for K.M. In such a case, independent counsel should be appointed when it becomes apparent to the trial court, either upon review of the guardian ad litem's report or at any point during the hearing, that the appointment is necessary in order to ensure a thorough, adversary exploration of the issues. The trial court's order is reversed and the cause remanded for a new hearing, with counsel appointed to represent K.M.

GROSE, C.J., and AGID, J., concur.

[2] Landlord and Tenant — Duty — Scope — Fitness for Human Habitation. A residential landlord does not have a generalized duty to use ordinary care to keep the leased premises fit for human habitation at all times during the tenancy. The landlord's fitness-for-human-habitation duties are limited to those duties specifically enumerated in RCW 59.18.060.


Nature of Action: A person who was burned after tripping and falling on a furnace venting pipe sought damages from the lessor of the premises.

Superior Court: The Superior Court for King County, No. 88-2-07385-6, Joan E. DuBuque, J., on June 11, 1990, entered a judgment on a verdict in favor of the lessor.

Court of Appeals: Holding that the lessor did not have a generalized duty to keep the premises fit for human habitation or a duty to repair the pipe and that the admission of a photograph was not error, the court affirms the judgment.

Eileen C. Susser, for appellant.

William W. Spencer and Murray, Dunham & Murray, for respondents.

WEBSTER, A.C.J. — Dana Aspon appeals the jury verdict returned in favor of the respondents, Edward and Pat Loomis, and the trial court's order denying her motion for a new trial. She asserts that the court erred in: (1) not instructing on her claim that the Loomises negligently failed to make a defective condition safe, (2) refusing to give Aspon's proposed instruction that a landlord has a duty to use ordinary care to keep the premises fit for human habitation at all times during a tenancy, and (3) admitting photographs of Aspon's breasts when the only
Exhibit O

Letter from Larry Jones, Ph.D., J.D.,
to Ashley's Dad (June 10, 2004)
June 10, 2004

Dear [Name],

ISSUE

Is it legally required in Washington to proceed to court and appoint a guardian ad litem or attorney to represent the interests of Ashley [Name] when any medical procedure is undertaken that will result in sterilization?

ANSWER

It is not necessary to have a court hearing on sterilization when the object of the medical procedure is not sterilization, but to obtain another medically necessary benefit.

Factual background. Ashley [Name] is a girl approaching her seventh birthday. She has "profound" developmental delay with mental retardation. Her developmental achievement is less than that of a typical child of six months, according to recent records of Children’s Hospital and Regional Medical Center. Also according to their records, "when one watches her with her parents there seems to be some positive interaction" (emphasis added). The important point is that physicians are uncertain whether she is even in touch with her environment enough to positively interact with the very individuals with whom she is most familiar and toward whom she would show love, if she could.

Ashley shows signs of premature puberty and you and her mother [Name] are proposing a set of coordinated medical procedures which will reduce her discomfort and increase her ability to remain in home care.

Thus, the report of the Ethics Committee at Children’s has stated that the potential benefits of a hysterectomy to Ashley are "to avoid the menstrual cycle, physical discomfort,
hygienic issues, confusion and anxiety in an individual unable to understand what is going on” and “to totally exclude the possibility of the patient being sexually assaulted and [that is, ‘with the result that she becomes’] impregnated.”

As the phrasing of this last point makes clear, there is no question but that for Ashley, the only possible kind of sexual interaction with a male would be a crime. She not only cannot reach what the law considers the mental capacity to consent to sexual activity, but she cannot even manifest a biological desire for sex. Her IQ is so low that it is untestable. This is factually very unlike persons with IQs 50 points higher, but who are frequently still adjudicated incapacitated and placed under a guardianship by a superior court.

Legal precedents. Washington’s modern law on sterilization begins with In re the Guardianship of Hayes, 93 Wn.2d 228, 608 P.2d 635, 641-42 (1980). That decision held that guardian could not direct the sterilization of a person under a guardianship unless there was clear and convincing proof that (1) she will be unable to understand sexual activity or control her behavior in the future; (2) there is no other form of contraception that is a reasonable and medically acceptable alternative to sterilization; (3) that sterilization would not have a detrimental effect on her future emotional or physical health; (4) that pregnancy would be physically or emotionally hazardous; and (5) she would not be capable of learning how to be a good parent.

Besides the fact that each of these points is obvious in Ashley’s case, compare the facts of the case that the court had before it in Edith Hayes. Even though Hayes is correctly described as “severely” mentally retarded, she is quite unlike Ashley.

Now 16 years old, [Edith Hayes] functions at the level of a four to five year old....Her mother and doctors believe she is sexually active and quite likely to become pregnant. Her parents are understandably concerned that Edith is engaging in these sexual activities.... [and] believe it is impossible to supervise her activities closely enough to prevent her from becoming involved in sexual relations.

This is the classic kind of case where the courts have discussed the legalities and procedures of sterilization – it is done for the purpose of avoiding pregnancy in a person who cannot fully understand its consequences or cannot raise a child with a sufficient degree of competence. Thus the court’s opinion rehearses at length the now discredited political policy of sterilization of inferior persons, associated both with the Nazis and, unfortunately, with the “eugenics” movement in early 20th century America. Nothing like the rationales for those policies is at issue in Ashley’s case.

The second Washington decision is about a woman similar to Edith Hayes and not similar to Ashley. In The Guardianship of K.M., 62 Wn. App. 811, 816 P.2d 71 (1991), the girl was 15 years old, she functioned at the mental age of 6 to 7-year old, and her I.Q. was 40. (This would be two to three standard deviations above where Ashley would score on an IQ test.)
K.M.’s independent functioning in various daily activities is severely limited. K.M.’s mother testified that K.M.’s compliancy and naivety cause her concern that K.M. may engage in sexual activity without the ability to make judgments regarding the consequences. K.M. currently takes birth control pills, but she needs daily monitoring.

Furthermore,

[a] counselor who met with K.M. regarding reproductive issues testified that K.M. expressed a desire not to have children because she felt she could not care for them... [A]lthough K.M. testified that she understood if she were sterilized she could not have a child, her testimony was ambiguous as to whether she understood the procedure was irreversible.

(Italics added.)

In that case the trial court held that the evidence did prove that it was in the best interest of K.M. to be sterilized. In reviewing the trial court’s decision the Court of Appeals did not answer the question of whether the trial court was wrong about sterilization being in her best interest, but instead sent the case back to the trial court, because there had not been an appointed lawyer who fought for the interests of K.M. with sufficient vigor.

But, of course, the facts in that case are radically different: that young woman is able to testify and can understand how hard it is to raise a child – unlike Ashley, who does not know what a child is and cannot talk.

In the case of K.M., it was ambiguous whether she understood that sterilization was irreversible. In Ashley’s case, it is ambiguous, according to the Ethics Committee, as to whether she is even attempting to communicate with anyone in her environment at all.

The third and last Washington case on sterilization is Morinaga v. Vue, 85 Wn. App. 822, 935 P.2d 637 (1997). Ms. Morinaga was a 25-year-old developmentally disabled woman with a full-scale IQ of 62. (This would be three or four standard deviations above where Ashley would score on an IQ test.) Morinaga had become pregnant the fifth time, when she had a tubal ligation. According to the Court of Appeals, from the records of her relationship with a physician, his records indicated that she appeared mentally impaired, slow to answer and confused. Again, this is quite unlike Ashley’s case, where the issue is not ambiguous. Morinaga testified that she wanted to deliver and have custody of the baby in the case at issue here. Again, that is totally unlike Ashley’s situation. Obviously, the object of the surgery was to prevent more pregnancies.

In that case, at the trial court level, the judge dismissed her entire lawsuit against the physician and officials who were involved. The Court of Appeals agreed that there was no proof of medical negligence and no battery had occurred by the sterilization, but sent the case back,
instructing the lower court to weigh the evidence or take more testimony on the issue of informed consent and a charge against the state officials involved.

CONCLUSION

The example of cancer. An instructive comparison can be drawn with ovarian cancer. There would be no question from anyone that a hysterectomy could be performed (or her ovaries removed) without the involvement of a court if Ashley were currently diagnosed with ovarian cancer. Thus, the three Washington governing cases must be read to allow sterilization when it is merely a byproduct of surgery performed for other compelling medical reasons.

Permanency of Ashley’s condition. An over-riding consideration in the cases above is the permanency of the decision versus the possibility that a woman could develop more skills at child-raising in the future. But here, medical opinion is united and unambiguous: there is no possibility that the relevant facts could change in Ashley’s lifetime. Ashley will never be able to learn to care for a child or even to understand the connection between sexuality and pregnancy. As a lay person, but one long interested in genetics, reproduction, and mental disability, I believe that medical developments make it much more likely that a way could be found in Ashley’s lifetime to restore her child-bearing capacity (through being a stem-cell donor, or some other way) than it is that we will learn how to increase her mental capacity to anything approaching that necessary to allow her to engage in any sexual activity.

It is also true that unlike the plaintiff in Morinaga, Ashley will never be able to seek the assistance of a lawyer to press a case against her parents. (I also remarked to you in passing how top plaintiff’s personal injury lawyers frequently decline to name Children’s as a defendant – as we declined in one case where a young woman with developmental disabilities died – because juries love Children’s and its physicians so much that including it as a co-defendant can destroy an entire case.)

Familial setting. I hope that this letter will be helpful in the difficult place that you, and Ashley are in. Ashley truly needs your loving care and I hope that you will be able to keep providing that to her in your home. Institutional and even other community settings are deadly by comparison. In addition to being the best in mortality studies, other studies of quality of care demonstrate that familial settings provide, on the average, the highest quality of care.

This conclusion is based on my training and experience before I became an attorney. I was a sociology professor and have published refereed articles on mental retardation, including its demography. I have kept familiar with mortality and quality of care trends and comparisons by remaining a member of the relevant professional societies, reading their journals, and conversing with physicians and other professionals in the field of cognitive disability.

Very truly yours

Larry A. Jones, Ph.D., J.D.
Exhibit P

Letter from Deborah A. Dorfman, Director of Legal Advocacy & Associate Executive Director, WPAS, to Jodi Long, Associate General Counsel, and Jeffrey Sconyers, General Counsel, Children’s Hospital (March 27, 2007)
March 27, 2007

VIA FACSIMILE AND FIRST CLASS MAIL

Jodi Long
Children’s Hospital
MS: S232
PO Box 50020
Seattle, WA 98145-5020

Jeffrey Sconyers
Children’s Hospital
MS: T-0111
PO Box 5371
Seattle, WA 98105-0371

Dear Ms. Long and Mr. Sconyers:

I am writing to follow up the investigation of the Washington Protection and Advocacy System (WPAS) pursuant to its probable cause authority under the Developmental Disabilities Assistance and Bill of Rights (DD) Act, 42 U.S.C. § 15041, et seq., into whether Ashley, the recipient of the “Ashley’s Treatment” was abused or neglected as a result of this treatment and whether her rights were violated.

At this time we are near the completion of our initial investigation and our report. Before we can complete our report, however, we have some additional requests for information. First, we request that you provide us with the information as to the total cost of the entire “Ashley’s Treatment” for Ashley and who paid for the treatment. Please provide any and all relevant documents relevant to such payment.

In addition, we would like to know whether any disciplinary action has been taken against any individual involved in providing the “Ashley’s Treatment” to Ashley or whether any sanctions have been imposed on any such individuals, whether through letters of reprimand, suspension, licensing complaints and violations, or any other type of action. WPAS is entitled to receive such information pursuant to its federal mandate so that it may conduct a “full investigation.” Specifically, the DD and Protection and Advocacy for Individuals with Mental Illness (PAMi) Act regulations permit protection and advocacy systems to obtain personnel information in regards to alleged abuse and neglect of individuals with disabilities. See 45. C.F.R. § 1386.22(b)(2)(iii). Please provide us with any and all documents and information regarding such

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1 All of the protection and advocacy Acts are to be read co-extensively. Thus the provisions of the DD Act and its regulations and the PAIMI Act and its regulations are to be read co-extensively.

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A Member of the National Disability Rights Network.
A substantial portion of the WPAS budget is federally funded.
March 27, 2007
Page 2

disciplinary, licensing, or related action. If no such action has been taken, please advise us of such.

Please provide us with the above-requested information within three business days of the receipt of this request as required by the DD Act. 42 U.S.C. § 15043(a)(2)(J)(i). Once we receive this information, we will be able to complete our initial report. We will complete our report by April 23, 2007 and deliver it to you on that date. You and your clients will have the opportunity to review the report and provide us with any comments no later than the close of business on April 30, 2007.

When we deliver our report to you we will provide a cover letter which will include a list of corrective actions that we will be requesting your clients to take. As you know, we have already made findings that your clients violated Ashley’s state and federal constitutional rights by failing to obtain a court order prior to performing the hysterectomy on her and also for the imposition of the entire “Ashley’s Treatment” on her without due process and a court order. We have also found that at the time that Ashley received her “Ashley’s Treatment” Children’s Hospital did not have the appropriate policies and procedures in place to ensure that her rights were protected. Once we complete our investigation, we will likely have additional findings.

As a courtesy to you and your clients, below, I am including a list of some of the requests that we will be making of Children’s Hospital in the cover letter that will accompany our report on April 23, 2007, so that you will have advance notice of these requests. Specifically, these requests include:

1. A written agreement that Children’s Hospital will immediately adopt a policy that prohibits the provision of Ashley’s Treatment at Children’s Hospital by any of its doctors or doctors contracting with or having privileges to practice at Children’s Hospital.

   In doing so, WPAS requests that Children’s Hospital administration agree to meet with representatives of the disability community, WPAS and WPAS’s medical experts so that WPAS, disability advocates and WPAS’s experts may have input into and can review the policy before it is finalized.

2. A written agreement that Children’s Hospital will immediately take, if it has not already done so, disciplinary action against the doctor who performed “Ashley’s Treatment” on Ashley without a court order. This includes, but is not limited to, filing a complaint with the Department of Health, as well as other disciplinary action.

3. A written agreement that Children’s Hospital will immediately adopt a policy that prohibits the sterilization of any minor for non-medical emergencies absent a signed court order. The policy must include a provision specifically stating that any sterilization that is ordered by a superior court cannot go forward until at least 30 days after the order is issued to allow for the minor to file an appeal of such an order. If the order is appealed, the policy must include provisions prohibiting the sterilization to go forward until all
March 27, 2007
Page 3

appeals have been exhausted or the individual states, in writing, by and through the child’s attorney or guardian ad litem, that the child will not be pursuing any further appeals.

We also request that as part of this policy, notice to the Washington Protection & Advocacy System (soon to be known as Disability Rights Washington) be given immediately upon the filing of a petition for sterilization of a minor with a disability for non-medical emergency reasons. Along with this notice, WPAS requests to be provided the cause number of the case and the court where the petition for sterilization has been filed. Further we request that this policy include provisions requiring Children’s Hospital to provide information to any minor for whom sterilization is sought about the WPAS (DRW), including the address and toll free telephone number at least fourteen business days prior to the initiation of court proceeding seeking sterilization.

In doing so, WPAS requests that Children’s Hospital administration agree to meet with representatives of the disability community, WPAS and WPAS’s medical experts so that WPAS, disability advocates and WPAS’s expert may have in-put into and can review the policy before it is finalized.

4. A written agreement that Children’s Hospital immediately revise its policies to ensure that a disability rights advocate is represented on the Hospital’s ethics committee. In doing so, WPAS requests that Children’s Hospital administration agree to meet with representatives of the disability community, WPAS and WPAS’s medical experts so that WPAS, disability advocates and WPAS’s expert may have in-put into and review the policy before it finalized.

Please bear in mind, however, this is not an exclusive list, and we may have additional requests after obtaining the above-requested information.

Additionally, we would like to arrange a meeting with you during the week of April 30th. Please advise us of your availability for a meeting that week as soon possible.

Thank you for your prompt attention to these matters. If you have any questions, please feel free to contact me at (206) 324-1521, ext. 241.

Sincerely,

Deborah A. Dorfman
Director of Legal Advocacy & Associate Executive Director

Cc: David Carlson, Associate Director of Legal Advocacy
    Mark Stroh, Executive Director-WPAS
Exhibit Q

Letter from Jodi Long, Associate General Counsel, Seattle Children’s Hospital and Regional Medical Center to Deborah A. Dorfman, Director of Legal Advocacy, Washington Protection and Advocacy System (January 23, 2007)
April 5, 2007

Deborah A. Dorfman
Director of Legal Advocacy & Associate Executive Director
Washington Protection & Advocacy System
315 – 5th Avenue South, Suite 850
Seattle, Washington 09104

Dear Ms. Dorfman:

I am writing you in response to your letter dated March 27, 2007, in which you request that we provide additional information in connection with your investigation of the “Ashley Treatment.” As Jeff Sconyers stated in our meeting yesterday, we do not believe that this request falls within the scope of WPAS’ legal authority, but we are nonetheless providing you responsive information in keeping with our mutual interest in resolving this matter in a collaborative fashion.

Earlier today, I sent David Carlson, via electronic mail, materials that set forth the hospital charges relating to the surgical procedures and identify the payor (copies are attached). As we discussed yesterday, we are unable to supply you with charge information for the pharmaceutical therapy, which is not provided in the hospital, but rather in the outpatient setting.

In response to your second request, Children’s Hospital has not taken action against any individual involved in providing the “Ashley Treatment.” While we have determined that corrective action is appropriate to ensure that the hospital has processes and safeguards in place to adequately protect the rights of our disabled patients and that our staff are well trained in this area, we do not believe that the conduct of any individual involved warrants disciplinary action.

I trust you will find this information helpful. I will be away from the office until April 19th and ask that you contact Jeff Sconyers at 206.987.2044 if you need further relevant information while I am away.

Very truly yours,

Jodi Long
Associate General Counsel

Enclosure

cc: Jeff Sconyers
    David Carlson
Exhibit R

Children’s Hospital Billing Report
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FAQAPR02

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Exhibit S

Curriculum Vitae of Scott Stiefel
Curriculum Vitae
February 2007

Scott Randy Stiefel, M.D.

I. PERSONAL DATA

Birth date: December 14, 1958
Birthplace: Denver, Colorado
Citizenship: USA
Children: Simon Fillat (30), Alejandro Melendez (25), Max Stiefel (15)
Address: 1467 Ute Drive, Salt Lake City, Utah 84108
Cellular: 801 541-9895
Pager: 801 914 6940
Email: stiefel@hsc.utah.edu

II. EDUCATION

Undergraduate
1976 to 1984: Colorado State University; B.S., Biology, 1984. Major Microbiology with concentration in Art (Printmaking)
1978: Kansas State University; study of architecture.

Graduate
1987: Stanford University; Documentary Filmmaking, Department of Communication.
1982: Colorado State University School of Veterinary Medicine; Department of Veterinary Medicine.
1984 to 1988: University of Colorado School of Medicine; Doctor of Medicine, October 1988.

Internship and Residency
1988 to 1994: Triple Board Residency (Pediatrics, Adult Psychiatry, and Child Psychiatry); University of Utah; Salt Lake City, Utah.

Specialty Board Certification and Eligibility
June 1995: Board Certified in Adult Psychiatry
June 1997: Board Certified in Child Psychiatry
June 1994: Pediatrics board eligible

III. PROFESSIONAL EXPERIENCE

Full and Part Time Positions
2005 to present: Inpatient Attending at University of Utah Neuropsychiatric Institute; adult and child inpatient psychiatry with specialty in developmental disabilities and mental illness
2005 to present: Consultation to the field in the areas of ethics, civil rights, treatment and program development in the areas of developmental disability and mental illness
1999 to present: Assistant Professor, Department of Adult and Child Psychiatry, University of Utah
1994 to 2005: Assistant Professor, Department of Pediatrics, University of Utah
2005 to present: Adjunct Professor, Department of Pediatrics, University of Utah
1994 to present: **Program Director of Neurobehavior Clinical Research Program,**
University of Utah, Department of Pediatrics
1994 to 2005: **Program Director of Neuropsychiatric Clinic for People with Developmental Disabilities,** University of Utah, Department of Psychiatry
1994 to 2003: **Medical Director for Division of Services for People with Disabilities,** State of Utah
1994 to 2005: **Consult Liaison** to Pediatric divisions of Neurology, Neurosurgery, Genetics, Metabolic Disorders, and Physical Medicine and Rehabilitation.
2000 to 2005: **Program Director of HOME Program and HOME Expansion programs,**
Medicaid Redesign Project,
University of Utah Neuropsychiatric Institute
*Area of specialization in all of the above positions: Global health care for individuals with developmental disabilities and genetic disorders*

**Hospital Staff Appointments**
1989 to present: **University of Utah Medical Center; Salt Lake City, Utah; Attending.**
1989 to present: **Primary Children’s Hospital; Salt Lake City, Utah; Attending.**
1991 to present: **University of Utah Neuropsychiatric Institute; Salt Lake City, Utah; Attending.**
1991 to 1993: **CPC Olympus View Hospital; Salt Lake City, Utah; Staff Physician.**

**Editorial Experience**
2000 to 2002: **Chair of Research Committee, National Association of Dual Diagnosis**
1999 to 2002: **Co-Chair of Products Committee, National Association of Dual Diagnosis**

**Research Awards**

**Funded Grants**
2004-2005 **HOME Project Expansion**; Expansion in partnership with the State of Utah to 500 individuals (see below)
2004-2006 **Long Term Care; Alzheimers Population; Center for Health Care Strategies/Robert Wood Johnson**; collaborative planning grant with State of Utah to apply HOME model to these populations
2000-2003 **HOME Project** (Habilitation Options and Medical Excellence); Funding sources, **Center for Health Care Strategies/Robert Wood Johnson**; Principal Investigator, Scott Stiefel, M.D. This is a Health Care Systems Grant for Medicaid Redesign. Initially, it was a consortium grant to the State of Utah for Medicaid redesign. We applied for and received the service delivery and research evaluation component of the grant that blends general medical, mental health and habilitative dollars into one funding stream to design and innovative health care system for individuals with developmental disabilities and co-morbid mental illness. The HOME Project involves coordinated care for 100 of the most complex individuals in the state of Utah. The service Medicaid contract costs of this group approach seven million dollars a year.
2000-2005 **Neurobehavior Clinical Research Program; Primary Children’s Foundation** and multiple other funding sources; Principle Investigator, Scott R. Stiefel, M.D.; An innovative program designed to provide longitudinal health care and outcomes research for children with severe developmental disabilities and behavior problems.
2004 **Citalopram in the Treatment of Adults with developmental Disabilities and Depression**, Phase Four Drug Study, Forrest. (elected to not complete study)
2001 **Autism Center of Excellence**; Funding source, NIH/ACC, The STAART Program; principal investigator, William McMahon, M.D.; This is a planning grant for the Utah
Center of Excellence for Autism and Developmental Disabilities. The implication of becoming a Center of Excellence opens the door for large amount of extramural funding. Dr. Stiefel's role was to serve as a consultant for the mental retardation component of the center. Attainment of Program Project grant was successful

2001 Education Research and Design Committee, University of Utah; $3,000
2000 Primary Children's Foundation Auxiliary Grant; $6,000
2000 Private unrestricted gift for research, Probst, $100,000
1994 to 2005: Neuropsychiatric Clinic for People with Disabilities: Contract with State of Utah, Division of Services for People with Disabilities for health care and research in the developmental disabilities, focused on mental health needs of this under-served population. This contract includes approximately $500,000 supports mainly clinical care
1997 to 2005: Contract with Department of Psychology for training of graduate students on Traumatic Brain Injury Training Grant; Janiece Pompa Ph.D. and Elaine Clark, Ph.D.

Research completed or in progress

10/2000 to Present: Pilot Studies Initially Funded by Primary Children's Foundation in Neurobehavior Clinical Research Program, (Scott R. Stiefel, MD, Principle Investigator unless otherwise noted)

1. Longitudinal outcome study, this study is our main clinical research project. Goals of the project are three-fold. First, this study investigates the efficacy of the program as a whole, as well as the various treatment approaches that are implemented in clinic. Second, it examines the developmental course of children with disabilities and the stability of their symptoms (behavioral, medical, etc.) over time. Third, this study explores how well we are serving our clients health care needs by assessing parent/caregiver satisfaction with the program. At this time, over 30 children are enrolled in the study. We have collected baseline data on all of them and are starting to collect data for our 6-month follow-up period. These children will serve as pilot subjects so that we can successfully apply for additional extra-mural funding in the near future. (In progress)

2. Behavior Analysis Laboratory (BAL), a state of the art human behavior lab was created in collaboration with two behavior specialists in the community, Robert O'Neill, Ph.D., Associate Professor, Department of Special Education, University of Utah and Alan Tribble, M.Ed., Behavior Specialist, Division of Services for People with Disabilities. This laboratory is used for both clinical and research projects. For example, parents, staff members, and students can covertly watch assessments through the observation mirror. Assessments or unusual/rare cases can also be taped for long-term study. The BAL is currently being used for a study that focuses on understanding the causes of problem behaviors (e.g., self-injurious behavior) in children with neurodevelopmental disorders. See below for more information about the project

3. Functional Assessment of Problem Behavior in Children with Neurodevelopmental Disorders, this study has two primary objectives. First, it will compare the efficacy of two types of functional assessment methods (interviews and experimental functional analyses) in identifying the consequences that reinforce problem behavior in children with complex health care needs. Second, it will collect data on the functions of problem behaviors of children with different neurobehavioral syndromes. The latter part of this study will enable us to assess diverse behavioral phenotypes using functional assessment methods and to relate these findings to specific genetic features. We have received approval for this project from the University's IRB and from the Department of Human Services. At this time, 23 children have participated in the study. The first genetic syndrome that has been targeted is Down syndrome. Ten of our participants have been diagnosed with Down syndrome.

4. Dietary Supplement Study, Center for Pediatric Nutrition Research, Department of Pediatrics, University of Utah, Laurie Moyer-Mileur, Ph.D., RD, Principal Investigator; assisted with data collection for their study investigating the use of dietary supplements in
5. Integrating functional assessment in evaluating the effects of medications to treat mental health issues in children with neurodevelopmental disorders
6. Phenotype-Genotype correlation blood collection and storage, partnership with William McMahon, MD and the GCRC
7. Cerebellar disorders and other genetic malformation of the central nervous system and co-morbid mental illness
8. Evaluation and Reduction of Polypharmacy
9. Investigation and description of behavior phenotypes such as Fragile X, Cri du Chat, Smith Magenis Syndrome, and genetic syndromes that cause Autism, Rubenstien Taybi Syndrome, Down’s Syndrome, Prader Willi, etc.
10. Description of Prevalence of Autistic Disorder and Tic Disorders in Children with Known Neurological Etiology; Exploration of Autism Sub-types
11. Documentary film projects including projects on the cultures of behavior phenotypes, brain development, documentation of behavior phenotypes, and cultural response to individuals with genetic disorders
12. Defining the Epidemiology and Presence of Medical Comorbidity and Psychiatric Dual Diagnosis in Adults and Children with Developmental Disabilities.
13. Review article: Neurobehavioral Presentations, Epidemiology and Treatment Strategies, (In Progress)

1999: Mecamylamine Study in Tourette’s Disorder William McMahon, M.D, Principle Investigator; multi site drug company sponsored research

1998 to present: Lead physician investigator on Robert Wood Johnson Health Care Systems Grant for Medicaid Redesign. Specific cell for delivery of health care and habilitative services to individuals with developmental disabilities and co-morbid mental illness. This is a grant to the State of Utah for blending of general medical, mental health and habilitative dollars into one funding stream to design an innovative health care system for this under-served population. Principle Investigator for complete Redesign Project, Julie Olson. RFP for service delivery portion will be released June of 1999

1997: ADOS Certification; University of Chicago, Cathy Lord, Ph.D.
1996: Tiagabine study in epilepsy with children. Drug company sponsored research for indication in children for partial epilepsy. Marsha Litzinger, M.D., Principle Investigator; part of multi-center study for FDA approval

1984 to 1986: Involved in the Study and Treatment of Overuse Phenomena in Musicians with Stuart Schneck, M.D.; UCHSC. (See special projects please)

1984 to 1983: Study of Peripheral Nerve Disorders using electrophysical and EMG techniques with Ray Whalen, D.V.M.; CSU School of Veterinary Medicine, Anatomy Department.

1983: Study of Treatment Protocols of Ocular Squamous Cell Carcinomas in Cattle and Equine Sarcoïd and Corneal Neoplasia using high frequency current induced hyperthermia with Robert A. Kainer, D.V.M.; CSU School of Veterinary Medicine, Anatomy Department.


IV. SCHOLASTIC AND COMMUNITY HONORS

2003: Frank J. Monolascino Award for Excellence Lifetime Achievement Award for Outstanding Leadership and Commitment to the Field of Dual Diagnosis, National Association of Dual Diagnosis

2002: Teacher of the Year, from Child Psychiatry residents, University of Utah

2001: Professional of the Year, for excellence in providing community-based professional services for people with disabilities, TKJ

1999: Election to the National Board of the National Association of Dual Diagnosis

1998: Person of the Year: State of Utah Department of Education, Division of School
Psychologists and Special Educators

1997: Outstanding Teacher Award, presented by Child Psychiatry and Triple Board Residents, University of Utah School of Medicine
1988: Dr. C. Henry Kempe Award for academic excellence, community service, and compassion for other human beings, particularly children
1984: Creative Art Scholarship for Creative Writing, Colorado State University
1983: Phi Beta Kappa; Sciences

V. ADMINISTRATIVE EXPERIENCE

Program Director
1994 to 2005: Neurobehavior Clinical Research Program, Primary Children’s Medical Center/UUMC
2000 to 2005: HOME Program and HOME Expansion, University of Utah Neuropsychiatric Institute
1994 to 2005: Neuropsychiatric Clinic for People With Developmental Disabilities, University of Utah Neuropsychiatric Institute and U of U Red Butte Health Clinics, Division of Services for People with Disabilities. Also served as Medical Director for State of Utah Division of Services for People with Disabilities

National Elected Boards
2000 to 2004: Member of Executive Directors Board, Department of Pediatrics, University of Utah Health Sciences Center

Forensic
2002 to present: Federal Court appointed mediator and monitor in Marr vs. Washington State

Teaching
2005 to present: Assistant Director of 1st Year Medical Student Curriculum in Psychiatry and Development, University of Utah Medical School

Conference Chair

Advisory Boards
2005 to present: Abbott Developmental Disabilities and Mental Illness

Chief Resident
1993 to 1994: Triple Board Residency, University of Utah Medical Center.

VI. PROFESSIONAL COMMUNITY ACTIVITIES
2005 to present: Expert consultation to ULS (Protection and Advocacy District of Columbia) regarding services at St. Elizabeths Hospital.
2002 to present: Federal Court Monitor for class action suit in Washington State. Federal court mediator and expert in this case and continue to work with the State in monitoring and technical assistance (Marr vs. State of Washington). Focus of the case is provision of mental health services to individuals with disabilities
1998 to Present: Consultation to the Utah State Hospital and Utah State Developmental Center
2002 to 2005: University of Utah Institutional Review Board (IRB)
2002: National Conference Chairman, National Association for Dual Diagnosis, Denver, Colorado, October 2002

2000: **Host and coordinator** of the 1st Annual Regional National Association for Dual Diagnosis Conference and Chapter formation, Salt Lake City Utah

2000 to 2003: **Board of Directors**, National Association of the Dually Diagnosed, Elected Western Regional Member


1998 to 2005: **Dual Diagnosis and ADHD Best Practices Committee**, State of Utah, Division of Mental Health

1998 to 2005: **Joint Committee on Developmental Disabilities and Mental Health**, Utah Department of Health and Human Services

1998 to 2003: **Maternal and Child Health**, State of Utah, Governor’s office


1997: **Rainman Committee**, Autism issues and legislative initiative in Utah

1994 to present: **Division of Services for People with Disabilities**, various committees and advisory boards

VII. **UNIVERSITY COMMUNITY ACTIVITY**

2002 to 2005: **University of Utah Institutional Review Board**

2000 to 2004: **Pediatric Executive Committee**

1998 to 2001: **Child Ethics Committee**, member, **Primary Children’s Medical Center**

1997 to 2000: **Chair of Neurobehavior Program Design Committee**

1998 to 2003: **Child Drug Study Work Group**, member, University of Utah, Bob Ward, M.D. Chair

**SPECIAL PROJECTS**

1995 to 2000: **Creation of Utah Tourette’s and Autism Research Group, Autism Program Project Grant** (side projects) with William McMahon, M.D.

1994 to 2005: **Neuropsychiatric Clinic for People with Developmental Disabilities**; Program Director; University of Utah; Design of clinic and services, creation of outreach network to serve individual in their communities throughout Utah

1993 to 2005: **Creation of Neurobehavior Clinical Research Program**; Program Medical Director, Primary Children’s Medical Center/UUMC; Salt Lake City, Utah; Design of clinic and services.

**SPECIAL PROJECTS DURING MEDICAL TRAINING**

1990 to 1994: **Combined Pediatrics and Psychiatry Continuity Clinic**; Clinic 6, University of Utah Medical Center; Supervisor, Michele Raddish, M.D.

1993 to 1994: **Developmental Clinic**; Primary Children's Medical Center; Salt Lake City, Utah; Supervisors, Michele Raddish, M.D., Charles Ralston, M.D.

1990 to 1991: **Teen Mom Clinic**; Clinic 6, University of Utah Medical Center; Salt Lake City, Utah

1987 to 1988: **Documentary Film at Stanford University**. Leave of absence from medical school to study Filmmaking. To prepare for future goals in patient, public and peer education. Director and Producer of **Age of Fruition**, a documentary that explores loss of function involved with aging.

1984 to 1988: **Musician’s clinic**. Member of the team that evaluates musicians for medical problems related to the particular demands of their profession. Director, Stuart Schneck, M.D.
VIII. MEMBERSHIP IN PROFESSIONAL SOCIETIES (Past and Present)

American Medical Association
American Academy of Pediatrics
American Psychiatric Association
American Academy of Child and Adolescent Psychiatry
AAMR
National Association of Dual Diagnosis
ARC

IX. TEACHING RESPONSIBILITIES

2005 to present: **Assistant Director of 1st year Medical Student Psychiatry and Developmental Curriculum and Teaching**, University of Utah Medical School

2000 to 2005: Co-Director of a curriculum (2 year cycle) development and teaching, University of Utah, Department of Child and Adolescent Psychiatry, Didactic Conference; **Normal and Abnormal Development Series**.

1999 to 2000: **Funded training of pediatric residents** through Pediatrics Primary Care Track Grant (Paul Young, M.D.) to teach management of children with developmental disabilities, chronic illness, and psychiatric co-morbidity.

1999 to 2005: **Dental Residency mini rotations**

1997 to 2004: **Traumatic Brain Injury Training Grant**; Janiece Pompa, Ph.D. and Elaine Clark, Ph.D.

1998 to present: **Didactic Conferences**, to residents

1997 to 2005. Invited special lecture series, **Brain and Behavior**, to residents

1995 to 2005: **Supervision of practicing primary care physicians in mini fellowships in developmental disabilities**.

1994 to present: **Supervision of medical students, residents, and fellows** including pediatrics, triple board, child psychiatry, adult psychiatry, and neurology (adult and child).

1994 to present: **Development of curriculum focusing on developmental disabilities** for pediatric, child psychiatry and adult psychiatry residents and fellows.

1994 to present: **Education regarding issues in individuals with developmental disabilities** through Division of Services for People with Disabilities. This includes case managers, professional care and habilitative providers, Utah State Legislature, and community primary care physicians.

1993 to 1994: **Introduction to Child Psychiatry**, medical students, University of Utah Medical School.

1989 to 1994: **Supervision of Medical Students**, clinical rotations, University of Utah Medical School.

BILIOGRAPHY

I. ORIGINAL PUBLICATIONS

2001 Stiefel, Scott R.; Interactive CD ROM development, *Seizure and Diagnosis and Differentiation of Pseudoseizures*; exploration of possibility of interactive CDROM genetic disorder diagnostic and education tool; multiple documentary film projects exploration surrounding disabilities issues. Currently negotiating content and publishing


1998 Stiefel, Scott R.; *Techniques of Psychical Examination of the Person who is Fearful or Protesting*, NADD Press.
II. BOOKS AND BOOK CHAPTERS
2006  American Journal of Medical Genetics, book chapter on Mental Illness and Behavior Phenotypes in Genetic Syndromes (in progress)
2006  A Parent Guide for Children with Developmental Disabilities and Severe Behavior Problems; currently negotiating with O'Reilly and Woodbine House

III. ABSTRACTS
2/2002  Rayls, K., Stiefel, S., & Williams, B.; Myotonic Dystrophy: An atypical case presentation. Paper was presented at the 30th annual International Neuropsychological Society convention, Toronto, CANADA.

IV. INVITED PRESENTATIONS AT SCIENTIFIC SOCIETIES
February 2007: Mental Illness in the Context of Genetic Syndromes, Montreal Canada
November 2006: Sleep disorders in Genetic Syndromes, National Association of Dual Diagnosis, Preconference Symposium
November 2003: Dual Diagnosis: Treatment of children and their families that have developmental disabilities and mental illness, Critical Issues Facing Children and Adolescents
October 2003: Prader Willi: California Chapter
August 2003: Prader Willi; National Convention
September 2002: Keynote, NADD conference, Lansing Michigan
October 2002: TBI psychopharmacology; Utah Association of Brain Injury
October 24, 2001: UNI HOME Project; the first year, NADD National Conference
April 10, 2000: Idaho Association of Developmental Disabilities 9th Annual Conference; Mental Illness, Epilepsy, Movement Disorder, and Behavior; Boise, Idaho.
May 4, 2000: ARC of Washington County, Intensive Behavior Management Program; Mental Illness, Epilepsy, Movement Disorder, and Behavior; Hagerstown, Maryland.
November 2, 2000: NADD 17th Annual Conference Keynote Address: Bridging the Gap: What do we know? What do we think we know? What don't we know? Where do we go? San Francisco, CA.
September 28, 2000: American College of Nurse Practitioners, National Clinical Symposium; Childhood Epilepsy. Salt Lake City, Utah.
April 3, 2000: Michigan State University Kalamazoo Center for Medical Studies, 16th Annual Developmental Disabilities Conference; Neurological/General Medical Causes of Behavior Problems in Persons with DD; Assessment Diagnosis & Treatment of Mental Illness in Persons with DD; Lansing, Michigan.
September 13, 1999: University of Utah Grand Rounds; The Fragile Brain: The Link Between Behavior and Mental Illness in Developmental Disabilities and Chronic Illness that Affect the CNS; Salt Lake City, Utah
October 15-16, 1998: TBI Conference, Brain Injury Association of Utah; Pediatric Advocacy: The Rest of the Story; Salt Lake City, Utah.

November 4-7, 1998: NADD Conference; Pre Conference: Techniques of Physical Examination of the Person who is Fearful or Protesting; Albuquerque, New Mexico.

July 10-12, 1998: 12th Annual Biological Basis of Pediatric Practice Symposium - Brain and Behavior: Genetics and Environment; Genetics and Behavior: What is a Behavior Phenotype?; Brian Head, Utah

November 8-14, 1997: ADOS-G Autism Training Workshop, University of Chicago, Chicago, Illinois (Training)


June 11-14, 1997: Bowman Grey School of Medicine, Epilepsy Conference, Winston-Salem North Carolina (Training)

April 22, 1997: AAMR Annual Conference; Park City, Utah

April 9, 1997: National Association of Social Workers

January 31, 1997: AAMR Lecture

November 4, 1996: Dual Diagnosis; Psychiatry Grand Rounds, University of Utah

November 1995: 12th National Association for the Dually Diagnosed Annual Conference; Early Identification and Diagnosis: A Lifespan Approach to Assessment and Intervention; Orlando, Florida

March 1995: Conference against Violence; Violence as it relates to missed or inaccurate diagnosis of medical and psychiatric conditions, lack of system communication and cooperation, physical and sexual abuse, and failure to recognize issues of post traumatic stress disorder in individuals with developmental disabilities; Utah Department of Human Services; Park City, Utah

November 1994: 11th National Association for the Dually Diagnosed Annual Conference; Conference luncheon speaker, The Utah Experience; Salt Lake City, Utah

October 1994: American Association of Mental Retardation Annual Conference; Region IV; Neuro-Developmental Perspectives on the Delivery of Health Care; Park City, Utah

INVITED PRESENTATIONS AT PROFESSIONAL ORGANIZATION MEETINGS

April 1995: Children with Special Health Care Needs; Dual Diagnosis and a Historical Perspective of Behavioral Pharmacology; Utah Department of Education; Park City, Utah

March 1996: Department of Mental Health; State of Utah; Park City, Utah

March 1996: Department of Human Services; State of Utah; Park City, Utah

April 1996: Department of Human Services; Boise, Idaho

April 1996: Combined Providers Conference; Park City Utah

April 1996: Division of Services for People with Disabilities; State of Utah

June 1996 to present: Coordination of regional conference for National Association for Dual Diagnosis to be held in April, 1998

April 11, 1996: ESI Management Conference

April 15-16, 1996: First Things First Conference; Boise, Idaho

January 9, 1997: DSPD Support Coordinator Training; Types and Causes of DD/MR, Diagnosis and Treatment of DD/MR, and Medication for People with Developmental Disabilities; Salt Lake City, Utah

January 28, 1997: Sugarhouse Rehabilitation Clinic

February 12, 1997: Special Child Fellows Lecture Series

April 14-15, 1997: First Things First; Boise; MI/DD Treatment Options; Boise, Idaho

May 7, 1997: Autism / Tourettes Syndrome Research Seminar

May 23, 1997: Mental Health Conference, Park City, Utah
August 7, 1997: DSPD Support Coordinator Training; *Types and Causes of DD/MR, Diagnosis and Treatment of DD/MR, and Medication for People with Developmental Disabilities*; Salt Lake City, Utah.

August 12, 1997: Division of Mental Health, Department of Human Services; Expert Panel on "Co-occurring Diagnoses of Developmental Disability and Serious Emotional Disturbance in Children and Youth"; Salt Lake City, Utah.


April 7, 1998: 1998 Conference of Organizations for People with Disabilities; *Tools for Obtaining Effective Mental Health Consultation and Treatment for Individuals with Dual Diagnosis*; Park City, Utah.

August 13, 1998: DSPD Support Coordinator Training; *Types and Causes of DD/MR, Diagnosis and Treatment of DD/MR, and Medication for People with Developmental Disabilities*; Salt Lake City, Utah.

November 9, 1998: Primary Children’s Medical Center Foundation Lectures; *Children with Special Health Care Needs Related to their Developmental Disabilities and Their Lifelong Medical Challenges*; Salt Lake City, Utah.

February 3, 1999: DSPD Support Coordinator Training; *Types and Causes of DD/MR, Diagnosis and Treatment of DD/MR, and Medication for People with Developmental Disabilities*; Salt Lake City, Utah.

February 10, 1999: University of Utah Department of Psychology; *Tourette’s*; Salt Lake City, Utah.

February 23, 1999: University of Utah Didactic Conference; Salt Lake City, Utah.

February 1999: Utah State Hospital Series on Mental Illness in Developmental Disabilities, part one.

February 26, 1999: Medical, Neurodevelopmental and Educational Intervention for Medically Challenged Children; *Medical Management of the Severely and Multiply Handicapped Child*; Salt Lake City, Utah.

March 18, 1999: Jordan School District Teaching Conference; *Emerging Trends in the use of Medication Treatment for Students with Disabilities*; Salt Lake City, Utah.

April 12, 1999: IAPDDA Conference; *The Future is Now-DDA Services Into the Next Millennium*; Boise, Idaho.

April 19, 1999: 1999 Conference of Organizations for People with Disabilities and NADD Preconference; *General Sessions Speaker*; Park City, Utah.

April 20, 1999: 1999 Conference of Organizations for People with Disabilities and NADD Preconference; *A New Look: Shifting Perspectives to Include the Possibility of Mental Illness*; Park City, Utah.

May 3, 1999: Intermountain Collaborative Transition Center Conference; *Mental Health and Disabilities in Young Adults*; Salt Lake City, Utah.

May 7, 1999: State Division of Mental Health Conference; *Fetal Alcohol Syndrome*; Park City, Utah.

June 2, 1999: RISE Professional Parents Training; *Tools for Obtaining Effective Mental and Physical Health Consultation and Treatment*; Draper, Utah.

June 10, 1999: Utah State Hospital; *Continuing Series Part Two, “Assessment, Treatment, and Diagnosis*; Provo, Utah.

June 17, 1999: Presentation to Primary Children’s Medical Center Volunteer Auxiliary Board; *Neurobehavior Program*; Primary Children’s Medical Center, Salt Lake City, Utah.

August 4, 1999: DSPD Support Coordination Training; *Types and Causes of DDMR,*
Diagnosis and Treatment of DDMR, and Medications; Salt Lake City, Utah
September 3, 1999: Critical Issues in Children and Adolescents: An Intervention Update;
Behavior Interventions Driven by Understanding; Salt Lake City, Utah
September 15, 1999: Developmental Center Dual Diagnosis Conference; Mental Retardation
and Co-morbid Mental Illness: Reframing Behavior as a Symptom; Provo, Utah
October 16, 1999: Autism Society of Utah; Compare and Contrast Autism, PDD,
Asperger’s, Landau Kleffner, and Other Related Disorders; Provo, Utah.
December 15, 1999: Abbott Laboratories; Anti-Convulsant Therapies in the New
Millenium; Salt Lake City, Utah.
Exhibit T

Agreement Between Children's Hospital and Regional Medical Center and Washington Protection and Advocacy System (Disability Rights Washington) Promoting Protection of Individuals With Developmental Disabilities
This Agreement between Children’s Hospital and Regional Medical Center ("Children’s") and Washington Protection and Advocacy System ("WPAS") (to be known as "Disability Rights Washington" as of June 1, 2007) applies to health care services provided or offered by Children’s to individuals with developmental disabilities. It is effective May 1, 2007.

1. **Background.** Children’s operates a non-profit hospital providing a full range of health care treatment to pediatric patients who primarily live in Washington, Alaska, Montana and Idaho. The patients served by Children’s include individuals with developmental disabilities. WPAS is a federally mandated private non-profit advocacy program that has been designated as the state of Washington’s protection and advocacy system. As such WPAS has the responsibility and authority to protect and advocate for the rights of individuals with developmental disabilities in the state of Washington. Children’s and WPAS share a strong commitment to the rights of individuals with developmental disabilities.

In 2004, Children’s, acting at the request of the parents of a patient known as “Ashley”, who is severely developmentally disabled, and after review and consultation within its Ethics Committee, performed a set of medical interventions to limit the ultimate adult size that Ashley will reach. These interventions included high-dose estrogen to cause early onset of puberty and the fusing of Ashley’s growth plates, along with a hysterectomy and breast bud removal. Children’s understands and acknowledges that sterilization of an individual with a developmental disability in the state of Washington requires a court order. In the case of Ashley, no court order was obtained.

Children’s has not offered and does not offer routine care to limit the growth of a developing child. Ashley’s case was, to the best knowledge of Children’s leaders, the first and only time such treatment has occurred. Children’s recognizes that therapy to limit growth is controversial, and understands that many people with disabilities strongly oppose its use, in any circumstances. In light of the moral and ethical questions posed by this care, Children’s has determined to enter into this Agreement with WPAS under which Children’s agrees not to undertake new growth limitation cases as described below, and to take other measures to assure protection of the interests of patients with developmental disabilities at Children’s.

Children’s has received and reviewed the WPAS report on Ashley and the treatment she received. In general, Children’s accepts the WPAS report. Specifically, Children’s agrees with the finding in the report that Ashley’s sterilization proceeded without a court order in violation of Washington State law, resulting in violation of Ashley’s
constitutional and common law rights. Children's deeply regrets its failure to assure court review and a court order prior to allowing performance of the sterilization and is dedicated to assuring full compliance with the law in any future case.

2. **Policy and Procedure on Growth-Limiting Medical Interventions.** Children's will develop, adopt and implement a policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities unless Children's has received a valid order from a court of competent jurisdiction, not subject to appeal, authorizing such intervention in a given specific case. In the event Children's does receive such an order providing legal authorization for one or more growth-limiting medical interventions for an individual with a developmental disability, Children's will in addition forward to its Ethics Committee for consideration any proposed use of such interventions. The Ethics Committee will review the proposed use and issue a report setting forth its recommendations regarding such interventions.

For purposes of this policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without a court order, the term "developmental disability" will have the definition set forth in federal law, 42 U.S.C. §15002(8)(A). A "growth-limiting medical intervention" means any medical intervention, including surgery or drug therapy, that alters or is intended to alter a patient's potential for normed physical maturation. The policy will apply whenever a growth-limiting medical intervention for an individual with a developmentally disability is sought by a parent, guardian, or other third party. In developing its policy, Children's will consult closely with WPAS. Children's will adopt its policy as soon as possible after this consultation, and expects to adopt it by September 1, 2007.

In developing its policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without a court order, Children's will include, to the extent feasible, the design and implementation of appropriate forcing functions within computer systems to prevent scheduling of breast bud removal surgery unless the requirements of Children's policy have been met. In addition, to the extent that Children's determines it is consistent with good clinical care to do so, and possible using Children's computer systems, Children's will design and implement forcing functions whereby any request made of Children's pharmacy to fill prescriptions for designated high dosages of hormone drug therapies will be monitored and reviewed by appropriate designated Children's clinical leaders for compliance with the policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without a court order. Children's pharmacy will not fill the prescription until it determines that it does not violate this policy.

To the extent permitted under federal and state laws regarding the privacy of health information, Children's will inform WPAS when it receives notice that a court order permitting growth-limiting medical intervention for a developmentally disabled individual has been entered. Children's will consult closely with WPAS to develop a procedure for providing this information.
3. **Corrective Actions.** Children's will take corrective actions to assure that in any future case involving the sterilization of an individual with a developmental disability, a valid court order not subject to appeal is in place. These corrective actions will include design and implementation of appropriate forcing functions within computer systems to prevent scheduling any such procedure unless the requirements of Children's policies have been met. Children's will also undertake educational activities to inform members of its medical staff and employees about a) the legal requirements in the state of Washington for court review and order before sterilization of an individual with a developmental disability; b) Children's policy (when adopted pursuant to paragraph 2 of this Agreement) prohibiting growth-limiting medical interventions for individuals with developmental disabilities without court order and c) bioethical considerations in limiting the physical growth of individuals with developmental disabilities.

4. **No Sterilizations Without Court Order.** Children's acknowledges that prior to performing surgery intended to sterilize an individual with a developmental disability, Washington law requires a valid court order permitting the procedure. Children's will adopt and implement a policy barring any sterilization without a court order except in emergency situations, and will require that all applicable appeals or appeal periods have concluded before proceeding with any non-emergency sterilization. In developing its policy, Children's will consult closely with WPAS. Children's will adopt its policy as soon as possible after this consultation, and expects to adopt it by September 1, 2007.

To the extent permitted under federal and state laws regarding the privacy of health information, Children's will inform WPAS when it receives notice that a court order permitting sterilization for an individual with a developmental disability has been entered. Children's will consult closely with WPAS to develop a procedure for providing this information.

5. **Ethics Committee Membership.** Children's believes it will benefit from adding to its Ethics Committee one or more individuals who can advocate for individuals with developmental disabilities. Within 60 days of receiving from WPAS its recommendation of one or more individuals to serve in this capacity, Children's will appoint an individual as a member of the Ethics Committee who can serve as this advocate. Children's will adopt and implement a policy requiring appointment of one or more such individuals to its Ethics Committee, and will consult closely with WPAS in developing its policy and making any such appointment. Children's will in addition encourage and authorize the Ethics Committee to bring in appropriate internal and external experts for consultation and discussion with the Committee whenever it considers issues affecting individuals with developmental disabilities. If WPAS chooses to make recommendations regarding other categories of professionals who it believes should be considered for membership on the Ethics Committee, Children's will consider such recommendations carefully and consult closely with WPAS regarding them.

6. **Term.** This Agreement will commence on May 1, 2007, and continue for an initial term of five years. Thereafter, this Agreement will automatically renew on its
anniversary date for additional terms of one year unless after the expiration of the initial term, either party gives at least 60 days prior written notice of termination.

7. **Dispute Resolution.** If any dispute arises under this Agreement, the parties will first meet informally and attempt in good faith to resolve the dispute timely by agreement. If such timely good-faith informal dispute resolution efforts are not successful, either party may submit the dispute to mediation in Seattle, Washington, before a mediator mutually acceptable to the parties and affiliated with JAMS (Judicial Arbitration and Mediation Service), or if no JAMS mediator is available, before another mutually acceptable mediator. The party requesting mediation will notify the other party of the request, and the parties shall promptly meet and select a mediator, but in no event shall selection of the mediator take longer than 30 days. The party requesting mediation will submit a formal request for mediation in the form of a letter to the other party, with copy to the mediator, on or within 5 business days following selection of the mediator. Mediation of the disputed matter shall occur within 30 business days of delivery of the formal request for mediation, unless otherwise agreed in writing by the parties or the mediator is unavailable. The parties will bear the costs of any such mediation equally. Following a mediation, if either party remains dissatisfied with the resolution of the dispute, that party may submit the dispute to binding arbitration in Seattle, Washington, before an arbitrator mutually acceptable to the parties and affiliated with JAMS, or if no JAMS arbitrator is available, before another mutually acceptable arbitrator. Unless otherwise ordered by the arbitrator, the parties will bear the costs of any such arbitration equally, but the arbitrator may make an award of fees, costs or both. The arbitration award shall be enforceable by court action in a court of competent jurisdiction located in King County, Washington. No proceeding for enforcement of this Agreement may be commenced before the final outcome of the arbitration described above.

8. **Publicity.** The parties will maintain the confidentiality of all patient health information exchanged between them as required by federal and state law. The parties acknowledge that the contents of this Agreement may be made public by either party. The parties will cooperate with respect to the initial public announcements regarding this Agreement and the report prepared by WPAS on Ashley and the treatment she received. In making public statements, neither party will disparage the other. While this Agreement in no way limits the ability of either party to make public statements about growth-limiting medical interventions such as those provided in the case of Ashley, and the facts about the treatment of Ashley that are not confidential under federal and state law, neither party will make any public statements that are inconsistent with the contents of this Agreement. In making such public statements, however, neither party will be deemed to have disparaged the other when discussing in general the “Ashley Treatment” (as that term is used in the report prepared by WPAS), sterilization, or any other growth-limiting intervention for individuals with developmental disabilities. Further, neither party will be deemed to have disparaged the other when quoting from the report prepared by WPAS, or when making statements based on and consistent with the report in content, tone and spirit. The provisions of this section will be binding on the officers, directors, trustees, employees and agents of the parties. Each party acknowledges that it is not responsible for the actions or statements of independent third parties. WPAS agrees that
Agreement Promoting Protection Of Developmentally Disabled Individuals

any statements made by any National Disability Rights Network (NDRN) employee during and the day of the press conference will be consistent with the Report in content, tone and spirit. For the purposes of this Agreement, WPAS will not be responsible for the actions or statements of any NDRN employee after the day of the press conference.

9. Notice. Any notice required to be given by either party under this Agreement shall be in writing and delivered in person or sent by certified mail to the other party at the address set forth below:

Children’s: 4800 Sand Point Way, NE
Seattle, Washington 98105
Attention: Jeff Sconyers
Senior Vice President and General Counsel

WPAS (DRW): 315 Fifth Avenue South, Ste. 850
Seattle, Washington 98104
Attention: Deborah Dorfman
Director of Legal Advocacy and
Associate Executive Director

EXECUTED by the parties as of May 1, 2007:

CHILDREN’S HOSPITAL AND REGIONAL MEDICAL CENTER

By Its

WASHINGTON PROTECTION AND ADVOCACY SYSTEM

By Its

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