

Legal Advocacy Highlights 2009

Issues of Interest to Individuals with Developmental Disabilities

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Topics for Discussion

- ❖ Federal Executive & Legislative Activities
 - ❖ Obama Administration and Disability

- ❖ Washington State Legislative & Judicial Updates
 - ❖ Children's Intensive In-Home Behavior Support Services (CIIBS)
 - ❖ *Sharon Allen, et al. v. Western State Hospital*

- ❖ University of Washington/ADD Network
 - ❖ Systems Change Task Force
 - ❖ Disability Studies Program

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Obama Administration and Disability

- ❖ Guiding Principle: Work to nurture a society that values the contributions of all citizens and residents.
 - ❖ Strengthen access to and improve quality of health care.
 - ❖ Promote access to community living services
 - ❖ Protect civil rights
 - ❖ Expand educational opportunities
 - ❖ Increase access to employment
- ❖ Progress to date
 - ❖ American Recovery and Reinvestment Act – funding for SSA, IDEA, Medicaid, VR
 - ❖ Executive Order repealing the Bush restrictions on embryonic stem cell research.
 - ❖ Christopher and Dana Reeve Paralysis Act – funding for NIH and spinal cord research
- ❖ Obama promised during campaign to sign and urge ratification of the UN *Convention on the Rights of Persons with Disabilities*.
 - ❖ On July 24, 2009, he did sign a "celebratory proclamation" and instructed the Ambassador to the UN to formalize the signatory process.
 - ❖ Following signature, the Convention (as an international treaty) must be ratified by the Senate which is a major, if not insurmountable task.

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Convention on the Rights of Persons with Disabilities and Optional Protocol

- ❖ History and Current Status
 - ❖ Written over six year period during 8 meetings of Ad Hoc Committee of General Assembly.
 - ❖ Adopted on 13 December 2006 and opened for signature on 30 March 2007.
 - ❖ Entered into force on 3 May 2008; Currently are 140 (62) signatories to Convention; 83 (40) to Protocol.
- ❖ What is it?
 - ❖ One of several UN Human Rights treaties specifically addressing marginalized groups—i.e., children, women, refugees, racial minorities.
 - ❖ Significant because it makes a "paradigm shift" in attitudes and approaches to persons with disabilities— moves away from viewing individuals with disabilities as objects of charity, medical treatment and social protection towards viewing individuals as subjects with rights, capable of exercising those rights.
 - ❖ Incorporates a very broad definition of disability and limits exercise of rights to no one.
- ❖ Implementation and Monitoring
 - ❖ Countries must designate a focal point in the government and create a national mechanism to promote and monitor implementation (Article 33).
 - ❖ A Committee on the Rights of Persons with Disabilities, made up of independent experts, will receive periodic reports from States Parties on progress made in implementing the Convention (Articles 34 to 39).
- ❖ Optional Protocol
 - ❖ If States Parties ratify, allows individuals or groups to file complaints with the UN Committee alleging violations of their rights under the Convention once national complaint mechanisms are exhausted.

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Guiding Principles

- ❖ Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- ❖ Non-discrimination
- ❖ Full and effective participation and inclusion in society
- ❖ Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- ❖ Equality of opportunity
- ❖ Accessibility
- ❖ Equality between men and women
- ❖ Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

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Disability Definition

- ❖ Preamble:
 - ❖ "Disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others."
- ❖ Article 1:
 - ❖ "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

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Discrimination

- ❖ Any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.
- ❖ It includes all forms of discrimination, including denial of reasonable accommodation.

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Equal Recognition Before Law

- ❖ Reflects the debates in the Ad Hoc Committees on “legal capacity” and “capacity to act.”
- ❖ Paradigm shift from assumption of incapacity (exclusion) to one of capacity (inclusion)?
- ❖ Not all human beings have the same capabilities but all can develop capacity with support. (Amita Dhanda)
- ❖ Does not preclude substituted decision making/judgment but also read in conjunction with other articles supports “universal capacity” (legal capacity and capacity to act).

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Article 12

- ❖ States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- ❖ States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- ❖ States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

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Why a UN Convention?

- ❖ A response to a development challenge—10% of the world's population are defined as disabled; 80% living in developing countries.
- ❖ Although other UN treaties include people with disabilities, these treaties were not used to ensure access to rights.
- ❖ CRPD mandates state parties take action; does not create new rights.
- ❖ Included in the duties required is development assistance by developed countries.
- ❖ Questions to consider:
 - So is it a hybrid—development document and human rights treaty?
 - If the USA ratifies, will it make any difference to Americans with Disabilities?

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Children's Intensive In-Home Behavior Support Services (CIIBS)

- ❖ Background
 - ❖ Increasing number of families requesting institutional placements for their minor children.
 - ❖ Advocates introduced legislation in 2008 for program based on Oregon's model waiver.
 - ❖ Legislation did not pass this but funding appropriated for 3 year period to begin the process.
 - ❖ Apply for new federal waiver
 - ❖ Use DDD assessment to identify families at risk
 - ❖ Families receive coordinated in-home supports so children can stay at home.

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Program Approach

- ❖ Intensive Case Management (family, service providers, school staff, other health providers, case manager, child are the support team).
- ❖ 30/60/90 day follow-up visits ongoing
- ❖ Program evaluation data collection
- ❖ Positive Behavior Support Model (PBS) utilized
- ❖ Behavior Support Providers (PhD or MA level therapists) and behavior technicians licensed by DOH.
- ❖ Collaboration between all support team members.
- ❖ New Services (therapeutic equipment, vehicle modification, specialized nutrition, clothing, AT) and Essential Services (behavior management consultation, staff/family training, planned respite).
- ❖ Average cost is 4,000 per month per child. Funding for up to 100 children in 2009-1010.

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Who is Eligible?

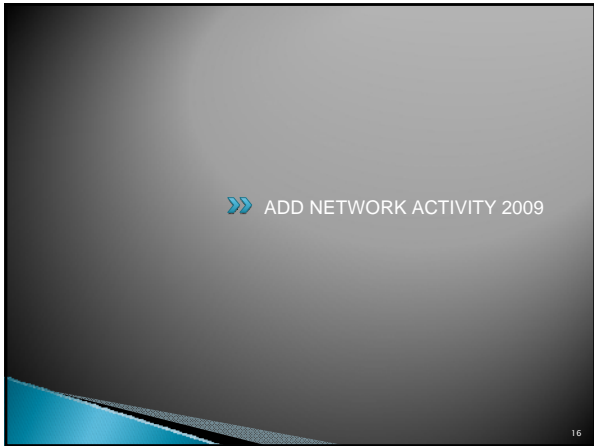
- ❖ Child 8-17 years who meets following as documented in DDD Assessment:
 - ❖ Caregiver Risk Score is Medium or Higher
 - ❖ High Behavior Acuity
 - ❖ Family Agrees to Participate in the Program
 - ❖ High or Severe Out-of-home Placement Risk Score
- ❖ DDD determines the Out-of-Home risk score by points including:
 - ❖ Diagnosis of Autism
 - ❖ Most prominent behavior=assault/injury AND severity=potentially dangerous or life threatening.
 - ❖ Level of monitoring required during awake hours = line of sight/earshot
 - ❖ Caregiver risk level=high or immediate
 - ❖ No other caregiver available
- ❖ Admitting 6 children per month across the state (began early June)

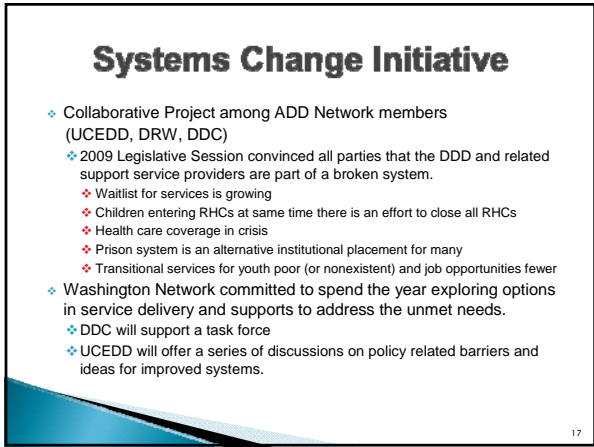
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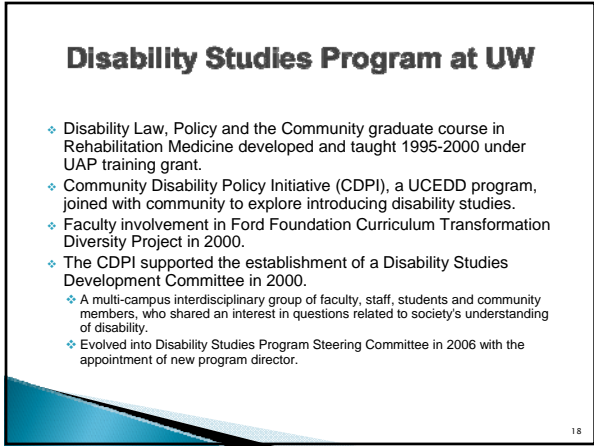
Sharon Allen, et al v. Western State Hospital

- ❖ Case originally filed in 1997 by Washington Protection & Advocacy System (WPAS) arguing inpatient care for individuals with dual diagnosis (mental illness and developmental disabilities) at Western State Hospital violated civil and human rights.
- ❖ A partial settlement reached in 2006 and DSHS agreed to limit the number of individuals (30 max) in "Habilitative Mental Health" unit of Western.
- ❖ Another agreement in which DSHS agreed to establish a quality assurance process for individuals living in the community.
- ❖ External monitoring and review followed and July 1, 2009 the case was dismissed.
- ❖ New policies and programs that have resulted from the complaint have improved the service delivery to this population of individuals.
 - ❖ Smaller number of inpatients allows for more individualized therapy
 - ❖ Improved access to community supports
 - ❖ Improved access to mental health therapy in the community

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Curriculum Development

- ❖ Introductory 300 level undergraduate course (Disability & Society: Introduction to Disability Studies) offered 2001.
- ❖ By 2004 we had three core course and a Disability Studies Minor under the Law, Societies and Justice Program.
- ❖ The undergraduate Disability Studies Minor provides an opportunity for students to develop a strong interdisciplinary foundation in the social, legal and political framing of disability.
- ❖ The emphasis is on studying the cultural construct of disability, social justice, and disability policy, and the intersections of disability, race, gender, sex, age, class and other markers of diversity and difference.
- ❖ Students enhance this foundation by studying disability through the arts, humanities, and the social sciences in elective courses.
- ❖ Internship and/or independent research requirement also.
- ❖ Fall 2008 we were approved for an interdisciplinary Disability Studies Major

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Program Goals – A Work in Progress

- ❖ **Teaching Goals:**
 - ❖ Provide the opportunity for students at all levels of the university to explore issues of disability through enrollment in courses, independent study, internships, and TA and RA opportunities.
 - ❖ Incorporate the study of disability into Undergraduate and Graduate education programs helping the University of Washington to fulfill its commitment to diversity.
- ❖ **Research Goals:**
 - ❖ Develop interdisciplinary scholarship, guided by a social model of disability that views the condition and experience of disability as deriving from a complex interplay of social, cultural, political, economic and biological determinants.
- ❖ **Community Education and Advocacy:**
 - ❖ Collaborate with existing community resources related to disability and foster partnerships among academic units and community programs.
 - ❖ Provide opportunities (such as seminars, conferences, speakers) to explore issues of importance that relate to the disability community within the political, social and cultural environment.

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Why the UCEDD was, is, and will be involved...

- ❖ Core faculty in Disability Studies are all staff/ faculty in UCEDD programs.
- ❖ UCEDD by definition is multidisciplinary as is disability studies.
- ❖ UCEDD responds to the needs of the community to extent we have the expertise and fits our mandate.
- ❖ UCEDD staff and faculty work in and with the health care system; opportunity exists to educate and advocate for providing health care from social/civil rights model.
- ❖ UCEDD emphasis on family and self-advocate involvement informs academic venues—i.e., Growth Attenuation Symposium in May 2007 and Eugenics Conference in October 2009.
- ❖ Disability Studies Program goals (teaching, research and community education) mirror UCEDD's core functions.

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In the end...we hope our students

- ❖ Will think about physical and mental differences differently.
- ❖ Will recognize socially imposed (and legal reinforced) values and beliefs regarding disability that result in "otherness."
- ❖ Will challenge the status quo and question assumptions regarding disability.
- ❖ Will be open to doing their part (including simply being aware of disability) to promote disability rights.

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Additional Resources

- ❖ Obama Disability Agenda
 - ❖ <http://www.whitehouse.gov/issues/disabilities/>
- ❖ Convention on the Rights of Persons with Disabilities
 - ❖ http://www.abilities.ca/human_rights/2009/07/21/obama_unconventionsigning/
 - ❖ <http://blogs.abcnews.com/politicalpunch/2009/07/obama-not-satisfied-with-progress-made-on-disabilities.htm>
 - ❖ <http://www.un.org/disabilities/>
- ❖ Children's Intensive In-home Behavioral Supports (CIIBS)
 - ❖ <http://www1.dshs.wa.gov/mediareleases/2009/pr09075.shtml>
- ❖ Disability Rights Washington (DRW)
 - ❖ <http://www.disabilityrightswa.org/>
- ❖ Washington State Developmental Disability Council (DDC)
 - ❖ <http://www.ddc.wa.gov/>
- ❖ University of Washington Disability Studies Program
 - ❖ <http://depts.washington.edu/dsstud/>

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