



# Disabilities Rights Center

Protection and Advocacy System for  
New Hampshire

Presentation For Advanced Leadership Series  
Sponsored by ABLE NH

by  
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# RSA 171-A, State Developmental Service Law-Enacted in 1975

- State must “maintain” and supervise a “state service delivery system” (SDS)
- SDS includes community living arrangements, day services, training, therapeutic, employment, service coordination, Area Agencies, and all components necessary to ensure appropriate care, protection from harm, opportunities for a quality life in the normal domains of community living.
- RSA 171-A establishes rights to those services in the SDS

## Rights under State Law, RSA 171-A include:

- A. Individuals with developmental disabilities have a right to “adequate ... habilitation and treatment, including such psychological, medical, vocational, social, education or rehabilitative services as his condition requires to bring about an improvement in condition **within the limits of modern knowledge.**” RSA 171-A:13 [QUALITY]
- B. Right to services that are individualized to persons needs interests and abilities. [INDIVIDUALIZED]
- C. Right to services in the least restrictive environment. [LRE]
- D. Right to timely provision of services [NO WAITING OVER 90 DAYS as of 7/10]
- E. Right to be free from harm, abuse, neglect
- F. Right to be deemed competent to manage affairs unless court declares incapable

# Examples of More Specific Rights in Regulations

➤ **503.8(b) All services shall be designed to:**

- (1) Promote the individual's personal development and quality of life in a manner that is determined by the individual;
- (2) Meet the individual's needs in personal care, employment, adult education and leisure activities;
- (3) Promote the individual's health and safety;
- (4) Protect the individual's right to freedom from abuse, neglect and exploitation;
- (5) Increase the individual's participation in a variety of integrated activities and settings;
- (6) Provide opportunities for the individual to exercise personal choice, independence and autonomy within the bounds of reasonable risks;
- (7) Enhance the individual's ability to perform personally meaningful or functional activities;
- (8) Assist the individual to acquire and maintain life skills, such as, managing a personal budget, participating in meal preparation, or traveling safely in the community; and
- (9) Be provided in such a way that the individual is seen as a valued, contributing member of his or her community.
- (10) The environment or setting in which an individual receives services shall promote that individual's freedom of movement, **ability to make informed decisions, self-determination, and participation in the community.**

# Rights to Services in Lay, Non-Legal Terms (include)

- A. Individualized Service Agreement spelling out services based on assessments of need, interests, abilities, aspirations
- B. Timely Initiation of New or Modified Services
- C. Residential living supports (with the presumption that most young adults will be able to move into residential arrangement in the community)
- D. Rewarding employment for most individuals , often with supports or rich day or avocational activities (and usually both)
- E. Community and Quality of Life Opportunities generally available to all folks
- F. Assistive Technology and Reasonable Accommodations

# Services' Rights in Lay, Non-Legal Terms (continued)

- G. Right to choice, self-determination and to be as independent as possible (with an environment, approach, and services that promotes those rights)
- H. Funding to pay for the supports or services but where possible and desirable reliance on natural supports
- I. Direct support and professional workforce that is qualified and suited
- J. High quality service coordination to make it all happen

# Dimensions of the Funding Problem

- For past 15 years for existing client services, only about two yearly rate increases have been given totaling 3-4%, yet costs have risen over about 50%.
- Funding even for waitlist has been sporadic meaning for most years, people waiting many months or years to be served, if served at all.
- Direct support staff, supervisory staff and service coordination wages very low making recruitment, retention of qualified workforce, turnover a huge problem
- Supported employment rates flat for past 10 or more years, despite increase in persons in service system

# Dimensions of the Funding Problem (cont.)

- More reliance on families to provide care, and with less supports and funding.
- Gutting of the infrastructure so necessary to ensure quality and safety
- Elimination of professional review teams
- Full time staff development trainers at Bureau and AA level from 15 to 1
- Reduced licensing staff by about 40%
- Availability of Professional Capacity particularly to address individuals with complex health, behavioral, communication, or assistive technology or community risk needs greatly diminished

# Renewing the Vision, prepared by BDS for Legislature and Governor Shaheen (2001)

- Held forums around the state
- Catalogued the huge problems and stresses associated with the waitlist families and individuals endured
- Vast majority of parents saw their children moving out when they were grown
- Documented need for a variety of housing options, not just enhanced family care
- More employment options for individuals
- Address wages of workforce
- More efficient and responsive quality improvement systems

# Governor's Commission on the Area Agencies (2005)

- Broad based group appointed by Governor Lynch of Area Agency and Government Officials, Provides, Family members, self advocate, DD Council, DRC, business community
- Made many of the same findings in Renewing the Vision, plus others
- Made 35 recommendations, pertaining to
  - Waitlist issue (no one should wait more than 90 days)
  - salary issues, training and supervisory and professional HR issues
  - Infrastructure issues
  - Quality Assurance, need for standardization
  - Central Registry
  - More housing options, supported
  - etc.

# 2006 Amendment to RSA 171-A: 1. Policy of the state that service delivery system should be based on:

- I. Participation of people with developmental disabilities and their families in decisions concerning necessary, desirable, and appropriate services....
- II. Services that offer comprehensive, responsive, and flexible support as individual and family needs evolve over time.
- III. Individual and family services based on full participation in the community, sharing ordinary places, developing meaningful relationships, and learning things that are useful, as well as enhancing the social and economic status of persons served.
- IV. Services that are relevant to the individual's age, abilities, and life goals, including support for gainful employment that maximizes the individual's potential for self-sufficiency and independence.
- V. Services based on individual choice, satisfaction, safety, and positive outcomes.
- VI. Services provided by competent, appropriately trained and compensated staff.

# Major SB 138 Statutory Requirements (applies to DD and ABD) (passed 2007)

- Effective July 1, 2009, New Requirements regarding service initiation and funding allocation.
  - For children exiting school who are clients of AA, funding must be allocated to them early enough so that new or modified services start upon graduation or exit from school
  - For others, funding for new services cannot exceed 90 days from development of service agreement
  - For clients already receiving services, new or modified services triggered by significant life changes, must be started no later than 90 days from service agreement amendment.

# Major SB 138 Statutory Requirements (cont.)

- Law requires that the “Legislature shall appropriate sufficient funds to meet such costs and requirements.”
- Legislative Oversight committee to track other timelines from point of application to eligibility and from funding allocation to start up of services
- Assistive Technology evaluations & annual screenings or evaluations thereafter
- Pay/rate increases for direct support staff and enhanced family care

# Major SB 138 Statutory Requirements (cont.)

## ➤ **Set up a Task Force**

- To recommend further salary increases and other human resource enhancements
- To develop quality outcome and performance standards and reliable methods to measure whether standards are being met
- To make recommendations on AA being sole provider and performing all functions

# Quickie Status Report on SB 138 Implementation

## ➤ Waitlist

- Funding for FY 08 and 09
- For FY 2010 & 2011, DHHS proposed funding to end waitlist permanently, Governor-Zero budget
- House subcommittee 3/25/09 recommended full funding for FY 2110 for W.L.; Zero so far for FY 2011.
- FY 08 2% rate increase went into effect; Gov. stopped 09.
- Assistive Technology Evaluations/Screenings?????
- DHHS budget proposed funding for salary and training recommendations; Gov. budget zero
- House Committee passed Quality Council bill

# BDS General Fund Requests For DD and ABD Wait Lists

	FY 2008	FY 2009	FY 2010	FY 2011
General Fund Requested	\$4,410,273	\$9,064,722	\$8,600,524	\$18,549,405
Individuals To Be Served	269	377	476	701
Total GF for the Biennium		\$13,474,994	Total GF for the Biennium	\$27,149,929

## Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget

- 1. It is the law, we are government of laws not of men/women.**
- 2. It is a law that has a strong moral and societal underpinning.**
  - Serving individual with DD is a long recognized societal obligation, codified in state & federal law in this state and part of the promise of closing Laconia.
  - All people need supports at various points in their life, most people with developmental disabilities, just need it on a more long term & intensive basis

# Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget (cont.)

## **3. The consequences of individuals not receiving community supports are more painful and costly, resulting in:**

- Regression, loss of skills, increase in challenging behaviors for graduates, who will now lack needed activity, instruction, and structure
- The expectation of continued growth, full or supported employment and independent living for many (indeed most) will be substantially delayed or in lost.
- For parents who now must stay home with their adult child there will be loss of income, health care, and maybe their home and more reliance on state or local public assistance.
- The stress on families will increase stress exponentially, creating mental health issues for caretakers, and siblings. Studies show increased abuse, divorce rates, etc.
- For elderly caregivers whose aging adult children desperately need residential placement, the hardship is enormous creating safety and health risks for both parents adult children

# Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget (cont.)

- For those families who cannot deal with the stress and don't have the savvy to obtain services, institutionalization of their adult children will result in highly inappropriate and generally more expensive facilities.
  - Facilities like New Hampshire Hospital and Glencliff, which both have increasing DD populations, nursing homes, ICF-MRs, nursing homes generally cost \$100,000 to \$225,000 annually vs. \$15,000 to \$100,000 for most community alternatives, \$43,000 average.
- More funding provides economic stimulus, putting money into the economy, resulting in more individuals being employed, both individuals with disabilities and direct support, supervisory and professional personnel.

# Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget (cont.)

## 4. **With respect to the issue of the need to sacrifice because of the financial crisis**

- Waitlisting individuals would be like turning away eligible children seeking enrollment in school or someone acutely ill being denied hospital admission.
- NH can and should do more. Consider—
  - The DD system had been grossly underfunded for at 15 years causing an erosion of service quality, poverty level wages for staff, high turnover etc.
  - entry level wages for direct support staff are \$8 to \$10 hourly compared state hospital which is at about \$14.
  - NH's level of fiscal effort (based on per capita wealth) is 34<sup>th</sup> in U.S. down from 10<sup>th</sup> 13 years ago.
  - NH's \$43,000 per person expenditure is well below all other New England States. Maine, the highest, is at \$84,000 per person

# Fiscal Effort Regarding DD Services Spending For Services Per \$1,000 Personal Income

<b>State</b>	<b>Spending Per \$1,000 Income</b>	<b>National Ranking</b>
<b>Maine</b>	<b>\$8.00</b>	<b>1st</b>
<b>Connecticut</b>	<b>\$7.66</b>	<b>3rd</b>
<b>Rhode Island</b>	<b>\$7.15</b>	<b>5th</b>
<b>Vermont</b>	<b>\$5.72</b>	<b>12th</b>
<b>Massachusetts</b>	<b>\$4.78</b>	<b>20th</b>
<b>New Hampshire</b>	<b>\$3.72</b>	<b>34th</b>
<b>National Average</b>	<b>\$4.12</b>	

**Source: Braddock, 2008**

**NH's DD Waiver per person cost compares favorably with the other New England States' average costs.**

<b>State</b>	<b>Average Per Person Waiver Expenditures*</b>	<b>Variance to NH</b>
Maine	\$ 84,203	\$ 40,609
Rhode Island	\$ 74,987	\$ 31,393
Connecticut	\$ 58,139	\$ 14,545
Massachusetts	\$ 58,045	\$ 14,451
Vermont	\$ 47,575	\$ 3,981
<b>New Hampshire</b>	<b>\$ 43,594</b>	<b>\$ -</b>
<b>Source: Braddock 2008 *2006 Data</b>		

## Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget (cont.)

### **5. With respect to the need to rely on volunteers and families**

- Natural supports should be utilized, however where not available paid supports need to be provided.
- Use and availability of natural supports will vary depending on community, individual or family choice, complexity of individual's needs, service coordinator or other personnel's time and resourcefulness
- Higher paid, stable and well qualified service coordinators and other personnel are needed to leverage and maximize natural or generic supports.
- Asking families of adults to shoulder more burden unfair, contrary to principles of independence, choice, what most families and adult children want.
- Rate of individuals in out of home community placement is less than the peak of the institutional placement era at Laconia (1970). Are we going backwards?

## Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget (cont.)

### **6. With respect to the issue that too much waitlist funding goes to individuals with forensic issues**

- Only about 1-2% of person receiving services have forensic issues
- Their cost is not dissimilar to others with complex health or behavior needs
- Improved infrastructure and treatment will reduce risk posed by this small subgroup.

# Points in Favor of Full Funding of Waitlist and Rest of Bureau of Developmental Service Budget (cont.)

## ➤ **Real Solutions**

- Stop the erosion; invest and restore the infrastructure which will lead to more independence and employment and creative use of natural and generic resources
- Improve education to children in special education system. For many this will mean less reliance on the AA system; for some it may mean no need for AA services.