

Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

The Division of Developmental and Behavioral Pediatrics (DDBP)
Cincinnati Children's Hospital Medical Center (CCHMC)
The University of Cincinnati (UC) University Center for Excellence in
Developmental Disabilities

Policy and Advocacy in the LEND Curriculum 2012-2013

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Policy Topics

- 1) Individuals with Disabilities Education and Improvement Act Part C
- 2) Money Follows the Person
- 3) Keeping Students Safe Act
- 4) Achieve a Better Life Experience (ABLE Act)
- 5) Convention on the Rights of Persons with Disabilities (CRPD)

Policy Topic #1: IDEIA Part C (Education/Early Intervention)

Trainees: Beverly Blosser, Beth Bishop,
Allison Stepp, Verity Rodrigues, Becky Hudock
& Zach Goble

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What is Part C?

- Overall Aims
 - Enhancing development of infants and toddlers with disabilities
 - Early Intervention as prevention
 - Maximizing independent living
 - Empowering families by building their skills
- Specific Services Provided
 - Free evaluation by a multi-disciplinary team
 - Creation of Individual Family Service Plan (IFSP)
 - Service coordination and provision
 - Creating transition plan by age 3

Impact on children with disabilities and their families?

- Positive Impact
 - Build family capacity to support child's development in their own context
 - Enhance developmental trajectory
 - Reduces cost for families, education systems, and communities
- Needs
 - Increased awareness of services
 - Decreased inclusion for qualification of services

How might Part C apply to my work?

- Refer for Early Intervention services
- Gives us an opportunity to be proactive versus reactive
- Increases effectiveness and collaboration during future caregiver/professional interactions
- Provide services and education for families

Discussion

- Current Developments:
 - Reauthorization of IDEIA is on horizon (last reauth. in 2004)
 - Reauthorization allows educators and policy-makers to examine benefits and current costs of IDEIA
 - AUCD has been meeting with different organizations to develop discussion points for next reauth:
 - Education in natural environments
 - Transition planning
 - Family inclusion

Policy Topic #2: Money Follows the Person (Olmstead Act/ Community Living)

Trainees: Dora Murphy-Courter, Amy Gladstone,
Allyson Somers, Julie Dunford,
& Joe Amaral

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What is Money Follows the Person?

- Medicaid Initiative resulting from the Olmstead court decision (Americans with Disabilities Act)
- Provides federal assistance for transition for services/supports which do not usually qualify for financial support under Medicaid

What is Money Follows the Person?

- Program to transition individuals out of institutions provides:
 - Intervention services
 - Support for cost of living
 - Medical costs
 - Housing
- Program varies from state to state
 - Not all states participate

Impact on children and adults with disabilities and their families?

- Provides more choice in care/least restrictive environment
- Increases use of home and community-based resources
- Coverage and specific restrictions vary between states
- SSI not affected for those in community
 - For those in facilities, SSI reduced to \$30/month

How might MFTP apply to my work?

- May limit access to specialized services
 - Require greater coordination between service providers
- Added resources for providers who may refer individuals for residential services

Discussion

- Current developments:
 - 29 states have implemented MFTP
 - 17 states have received grant money from the federal government, including Ohio
 - ACA (“Obamacare”) plans to expand this program and strengthen it through 2016 by providing \$2.25 billion more

Policy Topic #3: Keeping Students Safe Act (Education/ Restraint & Seclusion)

Trainees: Katie Bentley, Alison Heinekamp,
Allisson Moffett, Christine Tan

& Tanishia Williams **uceddLEND**

What is the Keeping Students Safe Act?

- Established federal minimum standards which limit the use of restraint, seclusion, and aversives in schools
- Promotes the use of school-wide positive behavioral interventions that have been shown to improve school climate and safety
- Prohibits the most dangerous types of restraint
- Limits the use of restraint & seclusion for emergency circumstances only (e.g., for risk to student or others)

Impact on children and young adults with disabilities and their families?

- Provides a safer environment in schools
- Decreases opportunities for accidental injuries/death
- Prevents unnecessary psychological stress/harm
- Makes a cultural shift towards preventive, positive intervention strategies

How might the KSS Act apply to my work?

- Physical protection for children/staff
- Legal protection for professionals
- Provide professionals with guidelines
- Guaranteed training for crisis intervention

Discussion

- Current developments:
 - No mention of an appropriation with this bill (No federal money for it yet)
 - Limited to just professionals in school settings
 - Committees are working to establish a set of minimum federal standards
 - At a hearing in June, Dan Crimmins (Georgia UCEDD) gave testimony against restraints (Full testimonial [here](#))

Discussion

- Ohio is currently calling for comments: All states must meet federal standards but may have higher standards
 - [Ohio call for Public Comment](#)
- Current issue in Congress (one bill in House and one in Senate) is whether restraints should be used at all
- Ongoing debate on restraint/seclusion to be included in students' Individualized Education Plans
- No current specifics about the quality/quantity of crisis intervention/positive behavioral supports training

Policy Topic #4: Achieve a Better Life Experience (ABLE) Act

Trainees: Sara Bitter, Stephanie Bowman,
Nicole Dupont & Erika Mellott

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What is the ABLE Act?

- Provision which provides individual with a similar account as a retirement fund but with different time limits
- Account stays with person during lifetime
- When person passes away, Medicaid gets paid first before money goes to the estate of the person
- The Achieving a Better Life Experience (ABLE) Act “...give[s] individuals with disabilities and their families access to accounts that would allow individual choice and control while protecting eligibility for Medicaid, SSI, and other important federal benefits for people with disabilities”- ABLE Act Fact Sheet

Impact on children and adults with disabilities and their families?

- Allows families to save for the future without losing the benefits that they receive
- Benefits are covered up to \$100,000
- Keeps families out of poverty
- Enables self-determination/freedom to make financial choices independently
- Covered expenses:
 - Education, housing, transportation, employment support, health and wellness & miscellaneous expenses

How might the ABLE Act apply to my work?

- With knowledge of the ABLE Act, we can provide necessary and appropriate resources for our families
- Freedom to recommend many more resources
 - Augmentative and Alternative Communication (AAC), therapeutic equipment, summer camps, groups, books

Discussion

- Current developments:
 - Introduced in 2011:
 - 35 sponsors currently in Senate with Sherrod Brown (OH) as one of the co-sponsors
 - 234 sponsors in the House including 13 representatives in OH

Policy Topic #5: Convention on the Rights of Persons with Disabilities (CRPD)

Trainees: Ashley Brazil, Amanda Fowler,
Ashley Shier & Emily Johnson

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What is CRPD?

- “A treaty that describes obligations of ratifying countries to promote, protect, fulfill, and ensure the rights of persons with disabilities.”
- Embodies features of the Americans with Disabilities Act

Impact on children and adults with disabilities and their families?

- **CRDP guarantees:**

- Equality and non-discrimination
- Access to buildings, schools, programs, and public transportation
- Community inclusion
- Right to personal mobility
- Freedom of expression and opinion and access to information
- Right to protection of privacy
- Right to participate in political and cultural life
- Right to be free from torture and cruel/inhumane punishment
- Right to respect for home and family
- Right to habilitation, rehabilitation, and healthcare
- Adequate standard of living and social protection
- Employment

How might CRPD apply to my work?

- Access to health care (rehabilitative and habilitative)
- Consistent international standards of care
- Access to information

Discussion

- Current developments:
 - US has signed, but not ratified
 - **Friday, October 26th** was the US ***Call-in and Tweet Day*** to support ratification of the CRPD (More information [here](#))
 - Does not create any new rights (compared to ADA)
 - Controversy related to home-school, marriage/family planning, health care