

Urban Institute Panel, Feb 5, 2008

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Outline of Remarks

- Challenges & Opportunities for Parents
 - Esp. of children with cognitive disabilities
- Challenges & Opportunities for Youth in Foster Care and/or Juvenile Justice
- Transition to Adulthood
 - Including when adults with special needs become parents themselves

For Parents - Challenges

- Finding the support needed to cope with your own feelings and needs
- Navigating multiple systems in order to get the information you need to make wise, informed decisions
- Knowing how to prioritize among competing needs to get the best mix of services for your particular child

Its All About Climbing the Mountain ~ not getting to the top

- Who sets the goals? Who sets the pace?
- How do you know when you arrived - There is always another mountain to climb
- How do you decide if you - and your child - are successful?
- Story of Wayne being placed in a classroom for hearing impaired children
- Story of George “may learn to write name, but not to graduate from high school”

WHERE ARE THEY NOW – Wayne outlived life expectancy, George college graduate, working in his career

Challenge for Parents - Knowing we have to work through pain

- We ask if we are prepared for wheelchairs, but do we ask if we are prepared for pain? Pain can be a path to healing & wholeness
- Do we want to risk confining our children to “emotional wheelchairs” in order to be kind?
- Comfort where we can, share the discomfort and challenge our children to strive for wholeness
- Alysia’s story – including 8 visits with Physical therapist – how to be creative with limits

WHERE IS SHE NOW – Berkshire Hills Music Academy

For Parents - Opportunities

- Believe in your own expertise
- Become your child’s primary advocate
- Learn when to fight and when to collaborate
- Become not only part of the team, but the leader of the team (example of 7 case managers)
- ADAM story – school, pediatrician, hospital

For Parents - Opportunities~ Create a Toolkit for Success

- Anger Management & Stress busting tools
- Problem Solving & Creative Thinking Tools
- Advocacy (& Self Advocacy) tools
- Relaxation, laughter & recreational tools
- Our own “AAA” club plan – looking upward and outward

Examples of Good Practice

- Grass-roots family organizations ala Family Voices www.familyvoices.org
- Family-to-family health information centers and Parent Training & Information Centers www.pacer.org
- Family-centered care - Medical home initiative - <http://www.medicalhomeinfo.org/>

Challenges For Children in Foster Care

- Health conditions and Educational needs often missed completely
- Or misdiagnosed
- Or diagnosed but treatment plan not implemented
- And then – starting over again, and again when placements change

Example: TR

- Missed 6 weeks of school while immunizations were being tracked down
- No dental care – 3 “first appointments” (over 2 year period) – no follow up
- Glasses – 17 months from exam to glasses in hand
- Multiple suspensions and failing grades but no evaluation for special ed needs
- No mental health services at all

TR was 1 of 3 siblings

- Over 2 years, the 3 children had experienced a combined total of 19 placements, including foster family homes and residential facilities, spanning a large geographic area, and multiple counties.
- They were separated and often lived up to 200 miles apart.
- They each had different caseworkers.
- Only 1 of the 3 received any mental health services, yet she was in care a year with no physical exam.
- Basic health information about one child, was not shared with the foster families or caseworkers for the other children.
- Dental & vision care was spotty and limited follow through
- Periods with no Medicaid and/or access to medical providers.
- Dozens of school changes
- Only one received special education services – none had complete comprehensive evaluation and IEP in one location
- They never attended their own court hearings, no record of judges inquiring about their health or educational needs and services

Opportunities & Promising Practices

- Training & supporting foster parents to become the child’s advocate in health, MH & education (PEATC) <http://www.peatc.org/>
- Involving bio family in appts & decisions

- Co-locating services (i.e. nurse in CW office)
- Equip judges to ask key questions via benchguides – NY (health) – Casey (education)
- Medical practices that specialize (i.e. in Rochester, NY)
- Use of Breakthrough collaborative approach
- Clearinghouse for best practice <http://www.cachildwelfareclearinghouse.org/>

Transition to Adulthood

- Equipping child to become their own self-advocate
- Moving from “family-centered” to “person-centered” model - <http://www.ilr.cornell.edu/edi/pcp/>
- Learning and engaging new systems – i.e. Vocational Rehab & Adult Basic Education
- Example: Trish

A few models

- Health & Ready to Work Initiative <http://www.hrtw.org/>
- Kids as Self Advocates <http://www.fvkasa.org/>
- Jim Casey Youth Opportunities Initiative <http://www.jimcaseyyouth.org/>
- Foster Club <http://www.fyi3.com/>
- Berkshire Hills Music Academy <http://berkshirehills.org/>
- Threshold Program http://www.lesley.edu/threshold/threshold_home.htm
- Vermont Work Incentive Initiative http://www.uiowa.edu/~lhpdc/work/States/Vt/Vermont_Overview_Presentation_Development.ppt

Money is often the biggest challenge

- Health coverage may end
- Financial aid for post-secondary education is limited
- Earning money from work may limit access to needed benefits esp related to health & MH

When Individuals with Special Needs Become Parents

- People with cognitive limitations CAN be good parents
- Children CAN do well in these families
- But to be successful, these parents will need unique approach to support & services
- Support should be given to the family as a unit, not just to the child

Examples of Positive Approaches

- Supported Parenting www.supported-parenting.com
- Positive Parenting Program at MA ARC: <http://www.arcmass.org/>

In Conclusion

- For parents of children with special needs, as well as for the youth themselves there are many challenges and many opportunities
- Some particular situations – including foster care, juvenile justice and transitioning into adulthood for all persons with disabilities – require additional supports and advocacy