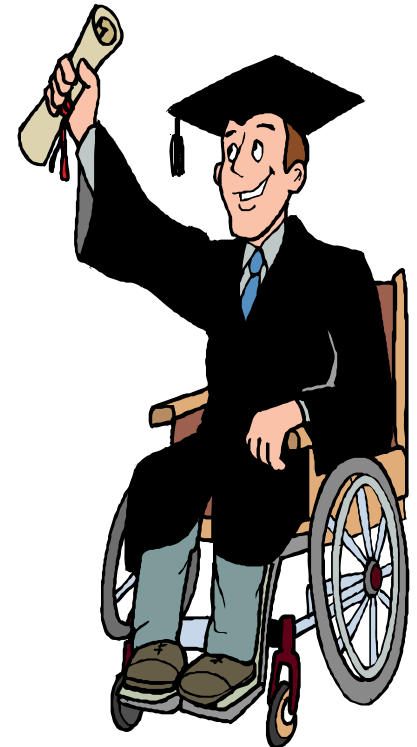
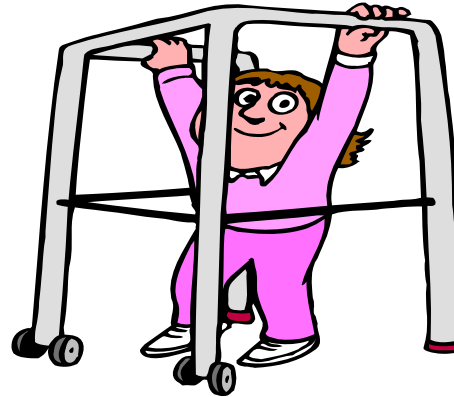


Adolescent to Adult Transitions: Trepidation or Triumph?

Penny Hauser-Cram
Boston College

Some Findings
from a
Longitudinal Study



The Early Intervention Collaborative Study (EICS)

- This is a longitudinal study of 150 children with developmental disabilities and their families from the time of Early Intervention services to age 23.
- This study is funded by the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, U.S. Dept of Health and Human Services.

The Early Intervention Collaborative Study(EICS) Data Collection Points

- **Time 1:** infancy –toddlerhood
- **Time 2:** age 1-2
- **Time 3:** age 3
- **Time 4:** age 5
- **Time 5:** age 10
- **Time 6:** age 15
- **Time 7:** age 18
- **Time 8:** age 23 (current)

Sample Description:
EICS at Age 18 (n>130)

- **Type of disability**
 - Down Syndrome 31.5%
 - Motor Impairment 37.6%
 - Developmental Delay 30.9%
- **Teen Gender: Male** 55%
- **Average Family Income** \$ 45 50k
- **Living in poverty** 20%
- **Parents: Partnered** 76%
- **Race/ethnicity: White** 89%
- **Teen Stanford Binet: Mean** 65.5
- **Teen Vineland: Mean** 59.7

Core Questions from the Early Intervention Collaborative Study (EICS)

- What have we learned about parent well-being? Implications for service provision
- What are parents' and teens' hopes and concerns about the future?



Parent Well-being: Do parents find raising their child to be stressful?

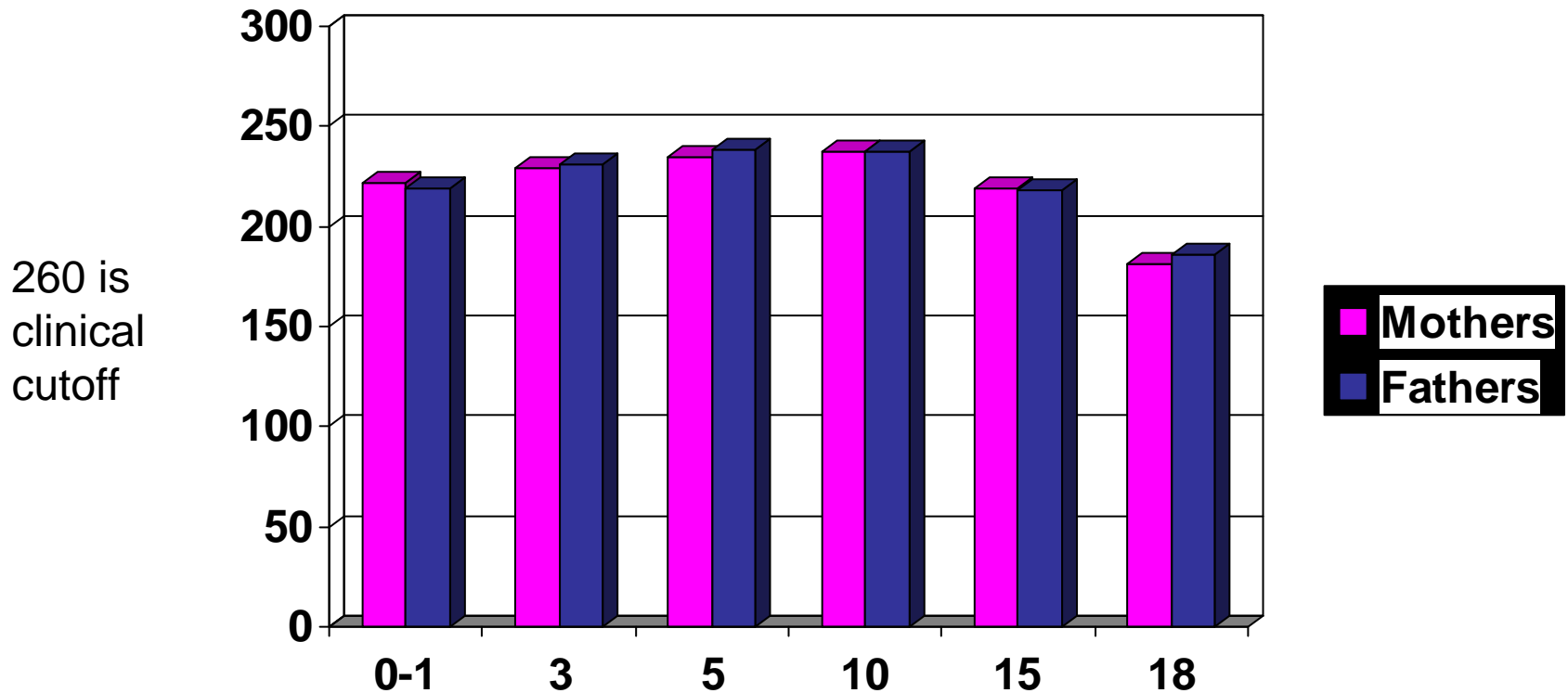
- Parenting Stress Index (Abidin):
 - Child-related stress (e.g., distractibility, demandingness, moodiness)
 - Parent-related stress (e.g., social isolation, restriction of role)

Assumptions from the literature

- Mothers experience higher levels of parenting stress than fathers.
- Both parents experience greatest levels of stress at the time of their child's diagnosis.



Parenting Stress in Mothers and Fathers Over Time



HLM: significant quadratic model at level 1. (Cronbach's alphas range .92-.98)

Points to ponder about stress: Implications for Improving Services

- Few significant differences between mothers and fathers-when they do occur, fathers have higher levels of stress. Fathers told us that they often felt left out of the service system.

The Voice of Fathers

- “I always go with (my wife) to visit our son’s pediatrician but the only time she [the pediatrician] will look at me or speak to me is when I hold my son in my lap. Otherwise all the communication is with (my wife).”



- The [service providers] just think that fathers are kind of like standing back and just kind of a third party through the whole thing.
We're not, we're right in there.

Points to ponder about stress: Implications for Improving Services

- On average, increases in stress are seen throughout the childhood period with decreases throughout adolescence. The highest levels of stress are found during the middle childhood period. Why does this occur?

Parents are Concerned about Children's Friendships During Middle Childhood

- (1) Has a group of friends? 31 %
- (2) Has been invited to a birthday party during the last year? 54%
- (3) Has been to a sleep-over during the last year? 40.7%
- (4) Self-reports being lonely at school: 71.6%

Siblings and other family members often serve as important friends and as core parts of social life.

Points to ponder about stress: Implications for Improving Services

- Parents on our Advisory Board suggest that stress levels will increase again for parents as their teens enter young adulthood and leave the school system.

Parents' Greatest Concerns about their Young Adult's Future

- (1) Receiving needed medical care
- (2) Finding meaningful employment
- (3) Having friends
- (4) Finding a good living situation
- (5) Access to community resources

Teens' (age 18) Expectations for Their Future

- At age 18, 97% were in high school full time (78% were on IEPs)
- At age 18, 49.2% had some form of paid employment, another 13.1% had volunteer positions
- About half (46.9%) expected to go to college or other post-secondary education

School Supports for Transition

- At age 18, 46% of parents report having no meetings with school personnel about post-high school plans.
- “For her it’s gonna get worse when the school is over, but I can’t imagine anything worse. I have a feeling I will be having to take on a bigger role of her care.”

Future Employment

- At age 18, parents listed the following as ideal employment for their teen in the future:
 - Working competitively: 32.3%
 - Working in supported employment: 35.5%
 - Working in sheltered work environment: 2.4%

Dilemmas about Employment

- “If you want him to have [speech and language] services then you have to put him in daycare and then he doesn’t do any work, he just sits in a room and we teach him how to brush his teeth. ...So I wanted him to work, I was told there was an opening in a restaurant...otherwise he gets to put heads on hungry hippos or count the marbles and bag them up or pour glue into Elmer’s glue containers.”

Having Friends

- At age 18, 26.9% report that their teen has no friends.
- “ I can’t go out and buy him a friend. I can’t make friends for him. And not only that you make your friends when you’re in school and they carry through with you into adulthood or then you’re making friends on the job. He has not been successful at finding a job....That’s been a big, big challenge for him.”

Experiences with Health Care Transitions

- At age 18, only a few parents reported any physician discussing health care transitions. When such discussions occurred they were viewed by parents as abrupt and dismissive.
- “You’re going from a child who has the same doctor all her life and then all of a sudden the doctor says, “You know what? She’s getting a little bit more difficult, she’s getting older. I’m a pediatrician. I don’t want to see her any more.”

Concerns about Community Services

- “I am majorly concerned about that. It took me ...7 months to even get an appointment. The state service that I use to call, all you get is a voice message. I’m really concerned about what services are there...in the future I would be very concerned if I wasn’t here.”

Future Living Situations

- At age 18, 72% of parents thought their young adults would move away from home in the future (most within 5 years).
 - 19.1 % in own apartment/home
 - 21.3% in college dorm
 - 23.6% in a community residence

Letting Go

- “She is protected...my feeling is that I know I’m going to have to let her go eventually. I think my biggest concern is I’m going to have to protect her from bad people and they’re everywhere....And they look for people like [Angela]. When she starts to get a little older and she starts to look for more freedom, I think I’m going to have a hard time letting go, “

Future Goals: Being Realistic and Supportive

- “[Dwayne] has grand plans, which I think is wonderful, that he has goals. He wants to attend college., he wants to get married, he wants to have children, he wants to live independently. So it’s going to be a balance of what he can do and what he can’t. It’s sort of scary to think about it.”

Hopes for Society

- “Being (my daughter’s) mother is a piece of cake. It’s dealing with the rest of the world and helping them, you hope, to even have a glimpse of her, to get a glimpse of who she really is...And for me the ultimate challenge is...can I get them to ever know, even vaguely, how spectacular she is.”