



**Families and Disability:  
Lifespan Changes and Implications for  
Intervention**

---

Laraine M. Glidden  
Distinguished Professor  
Psychology and Human Development  
St. Mary's College of Maryland



Disability Support Worker Conference, 2008  
Melbourne, Australia



**Acknowledgments**

---



- 249 families who participated
- Grant No. 21993 from the National Institute of Child Health and Human Development
- Many agencies who helped identify and recruit participants
- My home institution and dozens of students who have assisted this research over its 25 years



**Today's Talk**

---

- Project background and overview
- Highlight on findings
- Focus on lifespan changes and positive adaptation





**Background**

---

- Historical pathological view

Demands      **→**      Stress/Crisis



- Focus on negative evolved into an examination of what factors were associated with positive adaptation



**Background**


---

- Stigma associated with disabilities began to lessen
- Advocacy by families led to increased services
- Children with disabilities were fostered and adopted instead of institutionalized




### Unique Methodology

- **Adoptive-birth comparison**—Families knowingly adopt children with IDD
- If birth families have outcomes similar to those of families who have knowingly adopted children with IDD, then we can conclude that they are effectively coping with the reality demands



### Project Parenting Timeline

Time 1	Time 2	Time 3	Time 4
•Retrospective	•Personal Interview	•Mail or Telephone Follow-Up	•Transition to Adulthood
•Diagnosis/ Child entry report	•Self-report questionnaires	•Self- and other-report	•Self-report questionnaires
			•Behavioral Observations



### Sample Characteristics


Demographics	Time 2 (N=249)	Time 3 (N=188)	Time 4 (N=141)
Family Income (median\$/year)	40,000	50,000	67,000
Occupational Status (MSE12)	46.61	48.06	48.87
Mother Education (in years)	13.61	13.84	14.48
Mother Age (in years)	38.68	44.09	49.64
Child Age (years)	6.44	11.82	17.56
Anglo/European Children (%)	61.6	64.1	61.7
Child Level of Functioning			
Severe/Profound (%)	16	12.2	11
Mild/Moderate (%)	57	60.8	62.5
Borderline (%)	27	27	26.5

### Child Diagnoses

Diagnosis	%
Down Syndrome	37%
Cerebral Palsy	15%
Developmental Delay Unknown	9%
Brain Damage	3%
Epilepsy	4%
Other Chromosomal/Genetic	7%
Fetal Alcohol Syndrome	3%
Other	22%


### Mean Functional Ages at Time 4

- **Personal Self-Sufficiency:** 10.90 yrs  
-Assesses eating, cleanliness, toilet use, appearance, care of clothing, etc.
- **Community Self-Sufficiency:** 6.23 yrs  
-Travel, economic activity, language development, prevocational/vocational activity, etc.
- **Personal-Social Responsibility:** 7.03 yrs  
-Self-direction, responsibility, socialization



### Finding # 1

- Resilience may be extraordinary, but it is not unusual



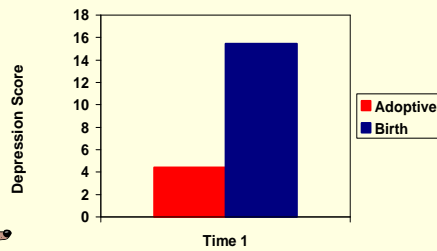
### Beck Depression Inventory (BDI)

- *Beck Depression Inventory (BDI)*--Beck, Ward, Mendelson, Mock, & Erbaugh, 1961)
- 21 items of ordered statements scaled from 0 to 3 in terms of the severity of the symptom of depression
- Score range: 0-63

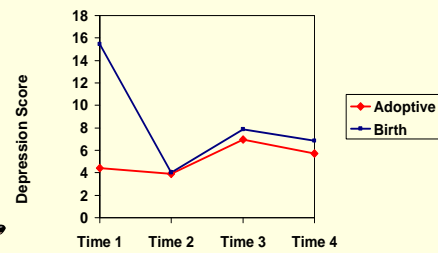
### BDI Sample Item

- 0 I do not feel sad.
- 1 I feel blue or sad.
- 2a I am blue or sad all of the time and I can't snap out of it.
- 2b I am so sad or unhappy that it is quite painful.
- 3 I am so sad or unhappy that I can't stand it.

### Depression at Time 1 For Adoptive and Birth Mothers



### Depression at Times 1-4 For Adoptive and Birth Mothers



### Finding # 2

- Rewards and satisfactions outweigh troubles and worries

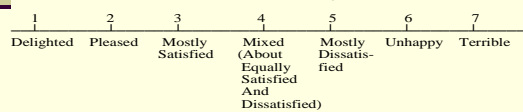


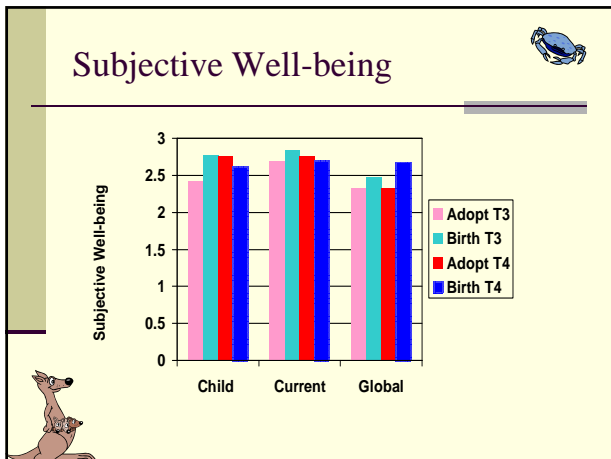
### Subjective Well-Being (SWB)

Three questions: Global, current, and with respect to the child

- 1) **Global:** How do you feel about your life as a whole?
- 2) **Current:** How do you feel about how things are going right now?
- 3) **Child:** How do you feel about how things are going with (child name)?

Lower scores = greater SWB





### Outcome Variable: Transition Daily Rewards and Worries

- Self-report inventory assesses the positive and negative aspects of a child's transition into adult life from the parent's point of view. 28 items divide into five factors:
  - Positive Future Orientation (PFO)
  - Community Resources (CR)
  - Financial Independence (FI)
  - Family Relations (FR)
  - Family Relations with Siblings (FR w/Sibs)

- ### TDRWQ Sample Items
- PFO:** I am excited by the prospects for my child's future.
  - CR:** I am pleased that \_\_\_\_\_ has adequate transportation.
  - FI:** I worry that \_\_\_\_\_'s income will be inadequate. (R)
  - FR:** I am sad that my child is missing out on important family interactions. (R)
  - FR w/Sibs:** I am glad that my children look out for one another.

### TDRWQ

	Mothers		Fathers	
	Adopt	Birth	Adopt	Birth
Positive Future Orientation	3.35	3.12	3.41	3.15
Community Resources	2.82	2.80	2.98	2.64
Financial Independence	3.00	2.84	2.99	2.77
Family Relations	4.07	4.15	4.02	4.12
Family Relations with Sib. Items	3.91	4.14	3.84	4.01

### Finding # 3

- Confrontive coping predicts positive well-being
  - Assertive efforts to alter the situation
  - May involve hostility and risk-taking

### Confrontive Coping—Sample Items

- Stood my ground and fought for what I wanted
- Tried to get the person responsible to change his or her mind
- I expressed anger to the person who caused the problem

### When Children are 12

- High levels of Confrontive Coping are related to low depression for mothers




### When Children are 18

- High levels of Confrontive Coping predict:
  - Better SWB-Child
  - Higher rewards for Family Relations




### Finding #4: Personality Predicts Coping Style

*NEO-Five Factor Inventory (NEO-FFI—Costa & McCrae)*


- Time 3 measurement
- Five factors: **Neuroticism, Extraversion, Openness, Agreeableness, Conscientiousness**
- There are 12 items scored on a 5-point Likert scale; scores range from 0-48.

### NEO-FFI Sample Questions

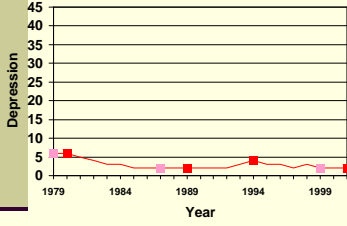
- I am pretty stable emotionally (R) (**Neuroticism**).
- I like to have a lot of people around me (**Extraversion**).
- I have a lot of intellectual curiosity (**Openness**).
- I generally try to be thoughtful and considerate (**Agreeableness**).
- I work hard to accomplish my goals (**Conscientiousness**).

### Escape-Avoidance

- Wishful thinking and behavioral efforts to escape or avoid the problem.
  - Refused to believe it had happened
  - Had fantasies or wished about how things might turn out
- Parents with high levels of neuroticism and low levels of conscientiousness are more likely to use escape-avoidance coping



### Resilience Case Study




Year	Event
1979	Birth
1980	Delay Identified (Time 1)
1987	Diagnosis
1989	Time 2 Interview
1994	Time 3 Interview
1999	Divorce
2001	Time 4 Interview

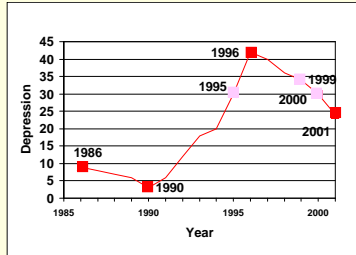
## Family 140

---

- Birth family
- Child characteristics
- At Time 1, Mom is very atypical for her group. BDI is only 6
- At T3, we learn that Neuroticism score is very low, only 7, and that marital satisfaction score is very high, 141.
- At T4, Mom's BDI remains low (2) despite a recent divorce and serious health problems with the target.



## Family 085 Timeline




Family 085 Timeline

- <1986: Preadoption
- 1986: Target Birth and Adoption (Time 1)
- 1990: Interview (Time 2)
- 1995: Parents Separate Welfare Assistance Miscarriages (5) Birth (Stillborn)
- 1996: Time 3 Interview
- 1999: Divorce Finalized
- 2000: Birth of Girl w/DS
- 2001: Birth of Son
- Time 4 Interview

## Implications for Services

---

- Families may experience extraordinary demands that accumulate over time
- The child/adult with IDD may be only one of many life events that parents must accommodate
- Understanding the context of the family's life is important in understanding their reactions to new events
- Working with existing personality traits can be useful in determining interaction approaches



## Conclusions

---

- Resilience is an ordinary and typical response to an extraordinary situation
- A positive psychology approach whereby we expect positive outcomes is a necessary and appropriate framework for working with families

