

# Promoting Resilience in Children with Intellectual and Developmental Disabilities

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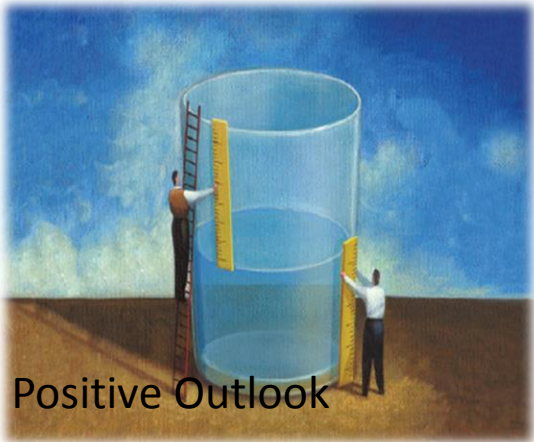
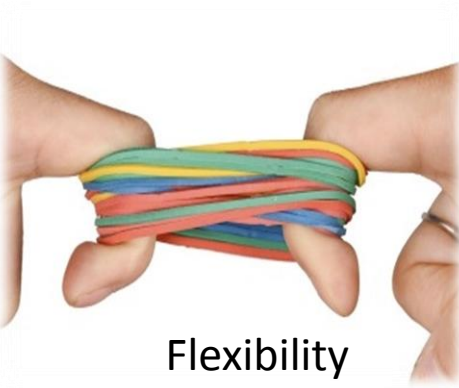
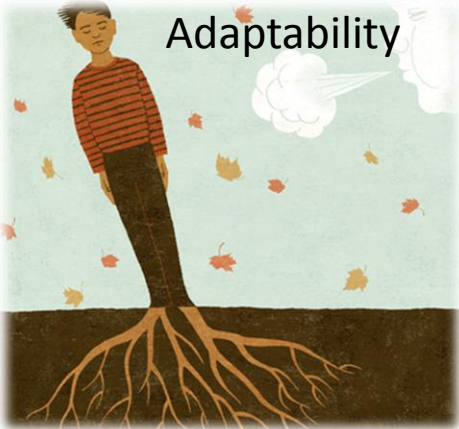
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# Objectives

- Identify the adverse psychosocial outcomes associated with the presence of I/DD
- Using an ecological framework, identify protective factors for individuals with I/DD at multiple system levels- individual, family, community
- Identify the core elements of Person-Centered Planning, a community-based intervention, and implement these in practice

# What is Resilience?



# What is Resilience?

- Achievement of positive, or better than expected outcomes, in the presence of risk and adversity
- A movement away from previous deficit-focused models of development which implied that exceptional qualities were needed to overcome adversity
- “Ordinary Magic”: employing normative adaptive resources to minimize the impact of risk factors on developmental outcomes (Masten, 2001)

# Risk Factors Associated with I/DD

- Mental Health difficulties:
  - Depression
  - Anxiety
- Social Isolation
- Economic Disadvantage

# Risk Factors Associated with I/DD

Abuse and Neglect: ongoing debate about the connection between I/DD and maltreatment

- Cross-national data of Child Protective Agencies: 1.7 times higher incidence among children with disabilities as compared to those without disabilities
- School-based data: children w/disabilities 31% prevalence and children w/o disabilities 9% prevalence; tendency to experience maltreatment at younger ages
- Need to recognize limitations in our current understanding of maltreatment among individuals with disabilities

“Disability is a natural part of the human experience . . .”

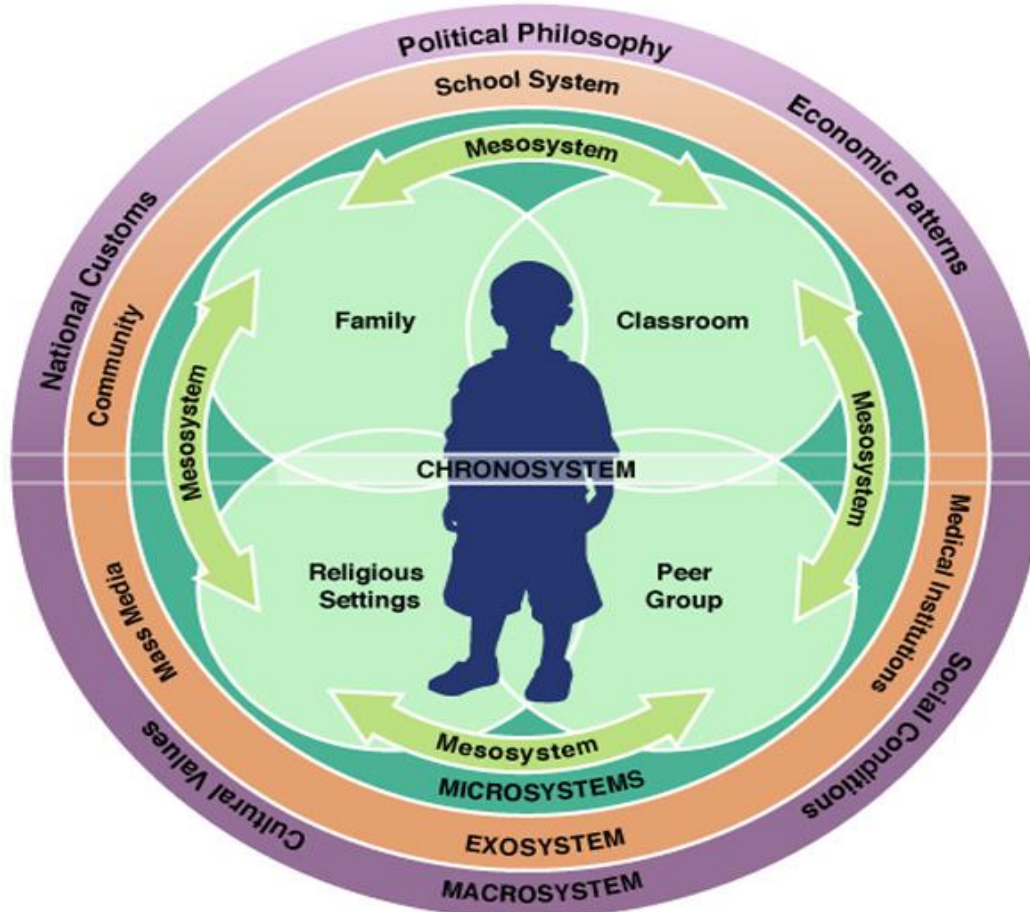


The Developmental Disabilities  
Assistance and Bill of Rights Act  
(2000)



# An Ecological Framework

Bronfenbrenner's Ecological Model of Child Development





# Resilience at the Individual Level

## Self-determination

- Ability to make choices and decisions
- Respect for preferences and interests
- Ability to monitor and regulate their actions
- Goal-oriented and self-directed

# Resilience at the Individual Level

## Practical Tool: Lifebook

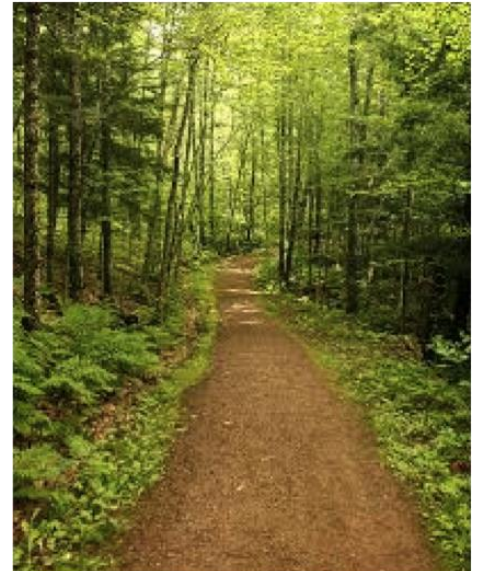
- A collection of words, pictures, mementos, documents
- An engaging, ongoing process of capturing an individual's personal history, interests, goals
- Easily adaptable to all levels of ability to support participation in it's creation
- Useful for summarizing important medical or educational history to be shared with providers
- Lifetime of Caring Project: individuals with disabilities who have aging parents and caregivers
- A therapeutic process for the individual to understand their disability and create the story they want told to others

# Resilience in the Family System

- Trauma: emotional response involving shock, helplessness after receiving a diagnosis
- Grief: loss of the 'hoped for' child

# Resilience in the Family System

- On the path towards resolution about a diagnosis
- A recurring process
- Resolution associated with secure attachment



# Resilience in the Family System

- Practical Tools: Support Groups for parents and siblings
  - Parents Reaching Out
  - EPICS Project
  - Sibshops

# Person Centered Planning: A Community-based Intervention

- A capacity-building process
- Never too late, never too early
- Core functions:
  - Listen
  - Understand
  - Act
- Originated to support transitions to post-secondary programming, but can be useful at any age, stage of life



# Models of Person Centered Planning

- MAPS
- PATHS
- Circles of Support
- Personal Futures Planning



# Person Centered Plans & IFSPs, IEPs, Transition Plans

- What's the difference?
  - IFSPs, IEPs, and transition plans are mandated by federal law for students who meet eligibility requirements for special education under IDEA
  - Person-centered plans can be used to support the special education programming process
  - Person-centered plans can be conducted at any point throughout a person's lifetime

# Person Centered Planning

## Define Relationships

Identify and define the child's important relationships:

- Family
- Friends
- Neighbors
- Therapists and teachers
- Spiritual leaders
- Who makes the child laugh?
- Who does the child go to when distressed, in need of help?
- Who does the child imitate?

# Common Pitfalls to Avoid



- Confusing relationships that are important to caregivers or providers with those that are important to the child
- Not organizing relationships based on roles (family versus therapists)
- Not updating relationships as they change over time

# Defining Relationships



# Person Centered Planning Organizing Meetings

## Creating a meeting structure:

- Who attends? Who is kept in the loop?
- Multiple, shorter meetings can be more effective than a single meeting:
  - Often questions arise that need to be addressed for the plan to move forward
  - Allows time for team members to process ideas and reactions
- If the child cannot attend, it is important to have some way to represent them:
  - Photo
  - Artifact: something they enjoy, something they created

# Person-Centered Planning Personal Profile

Create a personal profile of strengths, interests, supports:

- What do I like?
- What do I *love*?
- What do I not like?
- What do I *really* not like?
- What helps me at home, school, daycare, swim class?
- If I could choose absolutely anything I wanted to do today, how would I fill my day?
- What services am I getting now?
- What are my health needs?

# Person Centered Planning Goal Statements

- Team members generate goal statements:
  - Good rule of thumb: at least 3 goals
- Determine a timeline, with an endpoint and progress monitoring points along the way
- If necessary, prioritize goals to ensure feasibility



# Person Centered Planning Goal Statements

## Guiding questions for goal statements:

- In the future, where do I want to live?
- What activities do I want to do in a workplace, classroom?
- What kind of environment do I want to work in (inside/outside, sharing space with people/having my own space, noise level, active movement/sitting down . . .)?
- What activities do I want to do in my community?
- How do I want to get to places?
- What kinds of relationships do I want to have?

# Person Centered Planning Change Statements

- What changes need to happen to achieve my goals?
- Same rule of thumb: at least 3 change statements
- Where do changes need to occur?
  - New skills for me to learn
  - Means of access to programs, locations: economic, transportation
  - Meaningful inclusion: interventions for peers, training/technical assistance for program staff

# Person Centered Planning: Progress Monitoring and Accountability

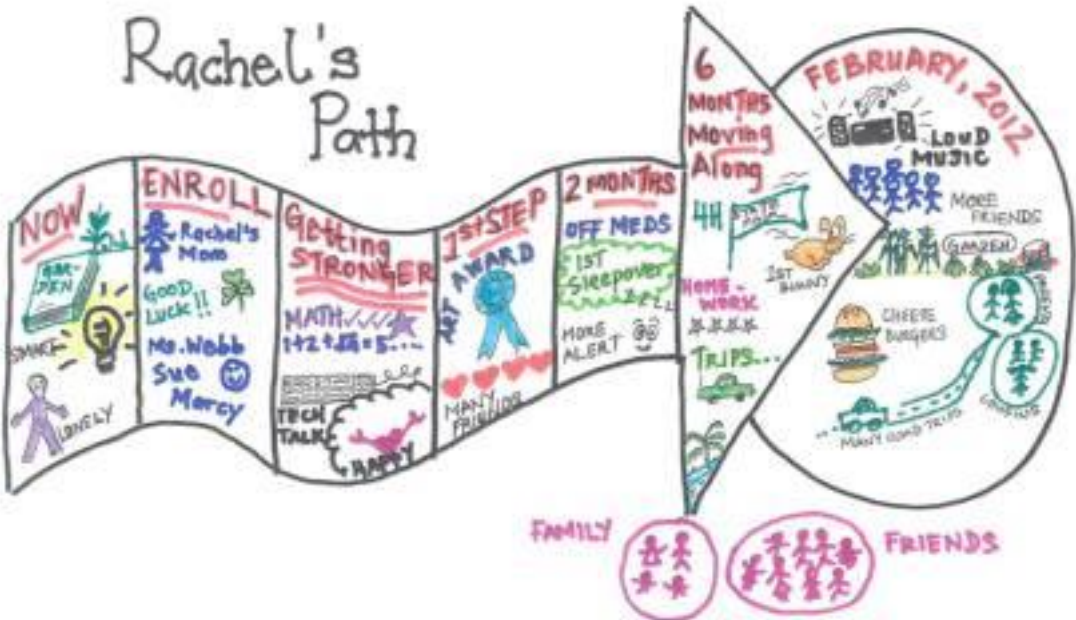
- Create action items and assign them to team members
- Facilitator monitors completion of action items
- How will we know when goals have been met?
- What are the benchmarks along the way?
- Who will meet and how often to evaluate progress?

# More Pitfalls to Avoid

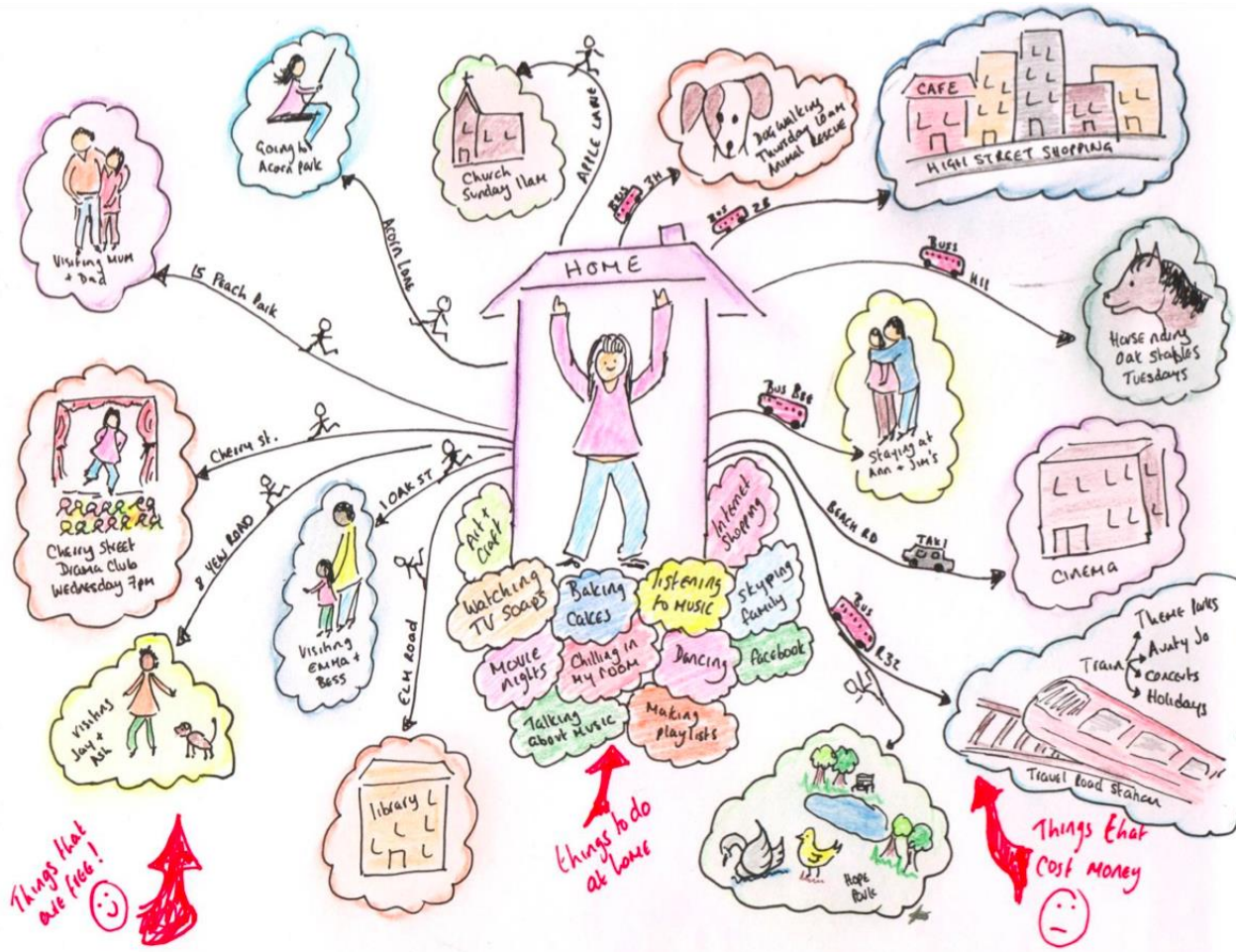


- Excessive Positivism
  - Unrealistic or unmet goals
    - Initial enthusiasm during planning stage is not maintained during later progress monitoring stages
  - Dissenting opinions are ignored or discouraged
  - Failures are re-framed as successes
- “Admiring the Problem”
  - Focusing on changes that are not relevant to the goals

# Examples



# Examples



# Resources

**Person Centered Planning Tool:**

[http://mn.gov/mnddc//extra/publications/choice/Its My Choice.pdf](http://mn.gov/mnddc//extra/publications/choice/Its_My_Choice.pdf)

**Cornell University Person Centered Planning Education Site:**

<http://www.personcenteredplanning.org/>

**National Gateway to Self-Determination:**

[www.ngsd.org](http://www.ngsd.org)

**Lifebooks:** [www.mo-sda.org](http://www.mo-sda.org), Lifebooks tab in menu

**Parents Reaching Out:**

[www.parentsreachingout.org](http://www.parentsreachingout.org)

**EPICS Project:**

[www.epicsproject.org](http://www.epicsproject.org)



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