Promoting Resilience in Children with Intellectual and Developmental Disabilities

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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?

Adaptability

Persistence

Flexibility

Positive Outlook
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
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

National Gateway to Self-Determination
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 its 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
Resources

Person Centered Planning Tool:

Cornell University Person Centered Planning Education Site:
http://www.personcenteredplanning.org/

National Gateway to Self-Determination:
www.ngsd.org
Lifebooks: www.mo-sda.org, Lifebooks tab in menu

Parents Reaching Out:
www.parentsreachingout.org

EPICS Project:
www.epicsproject.org
References


References


