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Supporting Families including Children with Disabilities: A Curriculum Module on Community Integration

Eileen M. Brennan
Portland State University

Julie M. Rosenzweig
Portland State University

Lisa Maureen Stewart
Portland State University

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Supporting Families Including Children with Disabilities: A Curriculum Module on Community Integration

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Eileen Brennan, PhD

Julie M. Rosenzweig, PhD

Lisa Stewart, MSW

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Portland, OR

Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services

National Institute on Disability and Rehabilitation Research, U.S. Department of Education

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Work-Life Integration Project Research Team

- Julie M. Rosenzweig & Eileen M. Brennan, Co-principal Investigators,
- Anna Malsch, Project Manager,
- Lisa Stewart, Graduate Research Assistant, and
- Daniel Coleman, Project Collaborator.

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Children with Special Needs

- 21.8% of families in the U.S. have a child with special health care needs (U.S. Department of Health and Human Services [HHS], 2008).

- 24% of those families with children who have health conditions report that it interferes with their daily activities (HHS, 2008).

- 9.2% of families in the U.S are raising a child with a disability (Wang, 2005).

- 13.5% of families caring for children with special needs reported spending 11 or more hours per week coordinating health care for their children (Child and Adolescent Health Initiative, 2004).

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Special Needs Increasing

- Approximately 5% of total population of pre-school aged children in 2000 received services under IDEA*

- From 1992/92 to 2000/01, the number of children receiving services under the IDEA increased substantially:
  - 3 yr olds, up 44%
  - 4 yr olds, up 37.6%
  - 5 yr olds. Up 22.4%
  - 6 to 11 yr olds, up 19%

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* IDEA: Individuals with Disabilities Act

Exceptional Care Responsibilities

- Refer to the experiences of caring for a dependent with a chronic illness or disability (Roundtree & Lynch, 2006).

- Include care that is:
  - *on-going*
  - *can persist into adulthood*
  - *is frequent and intense*
  - *often driven by crisis*
  - *can demand specialized knowledge*
  - *Can require costly medical/psycho-social interventions* (Lewis, Kagan & Heaton, 2000, Porterfield, 2002; Rosenzweig et al., 2008).

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Exceptional Care Responsibilities and Employment

- Approximately 33% of families caring for a child with special needs reported reducing their work hours or quitting their jobs in order to tend to their children's special needs (Child and Adolescent Health Initiative, 2004; Powers, 2003).

- In a survey of 349 caregivers of children with mental health disorders, 48% reported having quit work at some point to care for their child and 27% reported being terminated because of child-related work disruptions (Rosenzweig & Huffstutter, 2004).

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Family Strain Due to Exceptional Care

- Parents with exceptional care responsibilities report significantly more work-to-family and family-to-work conflict, less satisfaction with marriage, family, life and work as well as higher amounts of stress (Stewart, 2008).

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Community Integration

- Not just physical location in a community
  - *physical spaces*
  - *relationships*
  - *resources*
- Participation in key roles and activities. (National Center for Dissemination of Disability Research, 2004).
- Feelings of inclusion and belonging → Social Support.
- Full participation in workplaces and work roles, not constrained by caregiving responsibilities.

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Community Integration, Exceptional Care Responsibilities and Employment

- Families with exceptional care responsibilities report lower levels of social support than families with typical care responsibilities (Stewart, 2008).

- Community supports commonly available to parents of typically developing children such as child care and after-school programs are not always options for parents with exceptional care responsibilities (Rosenzweig & Brennan, 2008).

- Parents are often forced to accommodate their child's needs mainly through employment adjustments Rosenzweig, Brennan, & Ogilvie,2002).

- However, supports in the workplace often assume that the needs will be relatively short-term (Lewis, Kagan, & Heaton, 2000) .

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Barriers to Community Integration

- Barriers:
  - Lack of available or accessible resources
  - **Stigmatization: primary and courtesy**
  - Discrimination

- Consequences:
  - Increased isolation of family unit & individual members
  - Increased stress and strain on caregiver
  - Loss of socialization and social support
  - Reduced access to social capital
  - Lower quality of life

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Stigmatization Defined

- "Stigma results when people find others different from their definitions of self and conceptualize that being different, they are also inferior" (Fernandez & Arcia, 2004).

- Involves labeling, stereotyping, separation, status loss, and discrimination (Green, Davis, Karshmer, Marsh, & Straight, 2005; Link & Phelan, 2001).

- A cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses (President's New Commission on Mental Health, 2003).

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Effects of Primary Stigmatization

- Stigmatization leads others to avoid living, socializing, or working with, renting to, or employing people with mental disorders - especially severe disorders, such as schizophrenia. It leads to low self-esteem, isolation, and hopelessness.

- It deters the public from seeking and wanting to pay for care.

- Responding to stigmatization, people with mental health problems internalize public attitudes and become so embarrassed or ashamed that they often conceal symptoms and fail to seek treatment.
(President's New Commission on Mental Health, 2003)

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Courtesy Stigmatization

- Courtesy stigmatization (Goffman, 1963): the prejudice & discrimination extended to people associated with the person having the stigmatizing 'mark' (Norvilitis, Scime, & Lee, 2002; Corrigan, Miller & Watson, 2006).

- Also called "stigma by association," associative stigma," "stigma of affiliation" & "family stigma".

- Four domains of courtesy stigmatization: 1)interpersonal interaction, 2) structural discrimination, 3) public images of mental illness, and 4) access to social roles (Angermeyer, Schulze, & Dietrich, 2003).

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Parents' Lived Experience of Courtesy Stigmatization

The experience of courtesy stigma can be real or perceived

- *Enacted stigmatization*: overt acts of discrimination and rejection (Gray, 2002).

- *Felt stigmatization*: feelings of shame, blame, self-blame, embarrassment (Gray, 2002).

- *Subjective burden*: financial costs, logistical negotiations surrounding care responsibilities (Hinshaw, 2005).

- *Objective burden*: psychological distress related to caring for the family member (Hinshaw, 2005).

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Stigmatization and Parenting

- Stigmatization experienced by parents of children and adolescents with serious emotional or behavioral disorders is based on the social-cultural assignment of responsibility for children's private and public behavior to successful or deficit parenting.
  - Mothers compared to fathers are held more responsible for the behavior and mental health of children.
  - Stigmatization experience by vary by cultural identity.

- Success of parenting is culturally evaluated by the youth's matriculation into adulthood roles and responsibilities, as signified by the diminishment of the active parenting.

  (Gray, 2002; Fernandez & Arcia, 2004; Harden, 2005).

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Courtesy Stigmatization Management Strategies

- Management strategies used by parents related to associated stigma focus largely on controlling the dissemination of information regarding their child's mental health disorder (Gray, 2002).

  – Concealment and secrecy; passing: "normal appearing round of family life" (Birenbaum, 1970).

  – Limiting exposure to stigmatizing reactions of others, including limiting public outings, selective disclosure, & restricting socializing to others who would understand (Gray, 2002).

  – Levels of disclosure across domains, roles, & relationships.

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Family Support Defined

- Federation of Families for Children's Mental Health (1992) defines family support as a constellation of formal and informal services and tangible goods that are determined by families.

- Design and delivery of services is intended to support family members to lead healthy, balanced lives that are not burdened by the child with a disability or the requirements of services designed to help (Friesen, 1996).

- Family support should be family-defined, family-driven, and individualized to meet the unique needs of the family (Friesen, Brennan, & Penn, 2008).

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Family Support Core Principles

- *Family integrity and unity*

- *Family autonomy in choice and consent*

- *Family strengths*

- *Empowerment and participatory decision-making*

- *Cultural responsiveness*

- *Family-centeredness*

(Beach Center on Disabilities; Friesen, Brennan & Penn, 2008)

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Family Support Domains

- Family relationships
- Physical and mental health
- Physical health
- Employment
- Child care
- Education
- Economic support
- Community participation

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Sources of Family Support

- *Informal Supports*: e.g.. extended family, friends, neighbors, social networks

- *Formal Supports*: community-based programs, e.g., associated with health, mental health, social services, child care, education, recreation, economic

- *Family Network Supports*: parent support programs, family support organizations and networks, in person or virtual

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Preparing Social Workers
for their Roles with Families

- Collaborating with families to determine "whatever it takes" and secure resources necessary to care for a child or adolescent with a disability.

- Helping to fight stigmatization and discrimination.

- Working toward a community resource fit to promote integration (Barnett & Gareis, in press).

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When Families Attain Community Integration

- They draw what they need from the community (Kagan, Lewis, & Brennan, 2008).

- They fully participate in the community and can give back to community organizations through their participation (for example parent support groups).

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Major Teaching Resources

- Research and Training Center on Family Support and Children's Mental Health: Case study with discussion questions, PowerPoint slides and other resources.

- Sloan Work and Family Research Network: Work and family teaching materials on employed parents with children having disabilities.

- Beach Center resources on community integration.

- Resource and reference list

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