Promoting Community Integration: Learning Lessons from Other Disability Groups

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John’s Story

• Think of a story about a man named John who is 38 years-old and has been diagnosed with autism. Your story can include anything about how John thinks, feels, or behaves. The story should have a beginning, a middle, and an ending. Start your story with: Once upon a time.....
Goals

• Community integration of individuals with psychiatric disabilities
• Community integration theory and principles
• Strategies and programs that promote community integration
• How can these ideas translate into new policies, programs, and practices for supporting full community participation of individuals with autism spectrum disorders?
More people with psychiatric disabilities in the community (U.S. Data)...

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<tbody>
<tr>
<td>National</td>
<td>369,969</td>
<td>114,055</td>
<td>90,572</td>
<td>63,765</td>
<td>52,632</td>
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# of Individuals in State and County Hospitals at the End of the Year (From Annual report -- *Admissions and Resident Patients, State and County Mental Hospitals, United States*. Rockville, MD: Center for Mental Health Services)
…but *NOT OF* the Community

- Stigma and Discrimination Persists
- Housing
- Education
- Employment
- Financial independence
- Blocked rights
- Limited social roles
- Atrophied leisure/recreation
- Limited attention to spiritual issues
- Limited encouragement to vote
- Limited self-determination
Modest Residential Segregation: Poverty a Major Barrier

From Metraux, Caplan, Klugman, Hadley (2007)
Rights Blocked

• Review of state laws in 1999 pertaining to individuals with a mental illness and/or ruled as incompetent (increase in past 10 years)
  – 37 states restrict the right to vote
  – 44 states restrict right to serve on a jury
  – 24 states restrict the rights to hold public office
  – 33 states allow as grounds for divorce
  – 27 states allow as grounds for limiting parental rights

Hemmons et al. (2002). CMHJ.
SMI Associated with Greater Custody Loss  
(Park, Solomon, Mandell, 2006)

<table>
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<tr>
<th>Group</th>
<th>Any Child Welfare Contact</th>
<th>Out-of-home placement</th>
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<tbody>
<tr>
<td>SMI</td>
<td>14.6%</td>
<td>8.0%</td>
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<tr>
<td>Other MI</td>
<td>10.8%</td>
<td>3.8%</td>
</tr>
<tr>
<td>No MI</td>
<td>4.2%</td>
<td>1.6%</td>
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- Mothers with SMI 2.8 times more likely to experience out-of-home-placement than those without a MI

4,827 Philadelphia mothers eligible for Medicaid (7.2% had a SMI; 4.4% other MI)
Work Among Persons with a Psychiatric Disability

• Approximately 75-80% are unemployed at any given time
• Nearly 50% of those who do obtain jobs leave them within a one-year period
• Very few move beyond low-wage, part-time, minimal-benefit jobs
Financial Dependence and Poverty

- Nearly 70% of persons with a psychiatric disability are entirely dependent on entitlement programs.
- Largest disability group receiving SSA benefits - 40% of all beneficiaries have a psychiatric disability.
- Few people leave the SSA roles by moving into competitive employment – about 1%.
- Entitlements ($600-$900/mo) leave people well below the poverty line.
Community Integration

“The opportunity to live in the community, and be valued for one’s uniqueness and ability, like everyone else.” (Salzer, 2006)
Why promote community integration?

• **Moral perspective**: All creatures have equal value and worth whose potential should be maximized

• **Economic perspective**: The extent to which nations are economically developed is best assessed by the extent to which its citizens capabilities are maximized rather than they amount of goods produced

• **Evidentiary perspective**: People with psychiatric disabilities, would, could, and should participate
Would Participate

• Good place to live, work (70% want to work), and intimate relationships are top 3 things people want
• 80% report being extremely or very religious/spiritual (Corrigan et al., 2003; Salzer, 2005)
• 50% voted in 2004 election (Salzer, 2005)
• 50% have access to computers and the Internet and have attitudes comparable to the general population (Salzer et al., 2003)
• Parenting data (Nicholson, 2004)
Could Participate

• Participation-oriented supports initiatives have been found to be effective
  – Supported housing
  – Supported employment
  – Supported education
  – Consumer/peer-delivered supports
## Should Participate

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<tbody>
<tr>
<td></td>
<td>Higher quality of life, higher overall self-rated quality of life, more internal locus of control, and a better global functioning.</td>
<td>Eklund et al. (2001) – Persons diagnosed with schizophrenia</td>
</tr>
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<td></td>
<td>“...work contributes to the recovery process by providing meaning in one’s life...”</td>
<td>Provencher et al., (2002) – Psychiatric disabilities</td>
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<td></td>
<td>“...competitive work group showed higher rates of improvement of symptoms; in satisfaction with vocational services, leisure, and finances; and in self-esteem than did participants in a combined minimal work-no work group.”</td>
<td>Bond et al. (2001) – Diverse population</td>
</tr>
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<td></td>
<td>Formerly unemployed psychiatric patients who obtained competitive employment while participating in a vocational program tended to have lower symptoms, better overall functioning,</td>
<td>Mueser et al. (1997) – Diverse population</td>
</tr>
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**UPenn Collaborative on Community Integration**
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<thead>
<tr>
<th>Education</th>
<th>Significant increase in competitive employment; significant decrease in hospitalizations</th>
<th>Unger (1991) - young adults with long-term mental illnesses</th>
</tr>
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<tbody>
<tr>
<td>Significant increase in self-esteem</td>
<td>Cook (1993) – Severe mental illness</td>
<td></td>
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<tr>
<td>Achieve life goals, self-esteem, empowerment, meaning in life</td>
<td>Mowbray et al. (2002) – Diverse populations</td>
<td></td>
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<tr>
<td>Friendships and marital relationships</td>
<td>Friendships -- Enhanced quality of life, and ability to cope with life stressors and vulnerabilities</td>
<td>Boydell et al., (2002) – Diverse populations</td>
</tr>
<tr>
<td>-“Social support interactions were significantly associated with better satisfaction with social life…while negative interactions were associated with poorer overall life satisfaction, satisfaction with leisure and satisfaction with finances” (p. 415)</td>
<td>Yanos et al., (2001) – “Severe mental illness”</td>
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<tr>
<td>Having a close friend and having a friend providing help were more highly correlated with general life satisfaction. Marital status also associated with higher general life satisfaction</td>
<td>Kemmler et al., (1997) - Schizophrenia</td>
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Should Participate

| Parenting | -81% felt that becoming a mother was a positive event - advantages of having children – 1) child gives love to mother; 2) mother provides child with a chance to grow and develop; 3) child provides mother with a chance for personal growth; 4) children provide roots and immortality; 5) mother gives love to child  - how having a child changed your life – 1) motivates mother to be responsible, grow as a person; 2) keeps mother from drugs, deviant lifestyle; 3) child provides support - most women mentioned positive feelings produced by their children’s mere existence, rather than from what the children achieved or produced - several mothers indicated that their children were a strong motivating force in their own recovery - motherhood can be a resource because it provides a connection to the social world and implies achievement of an important adult role | Mowbray et al., 1995) – 24 mothers with serious mental illnesses  **Research shows that having children is associated with decreased life satisfaction while they are in the home and Simon, 2008 data shows that childless couples are happier than those with children |

UPenn Collaborative on Community Integration
### Should Participate

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<thead>
<tr>
<th>Topic</th>
<th>Description</th>
<th>Source</th>
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<tr>
<td>Religion/Spirituality</td>
<td>“...positively associated with psychological well-being and diminished psychiatric symptoms..., and significantly related to recovery, social inclusion, hope, and personal empowerment.”</td>
<td>Bussema &amp; Bussema (2000)</td>
</tr>
<tr>
<td></td>
<td>“Religious salience was positively related to empowerment, and religious service attendance was tied to increased use of recovery-promoting activities.” Recommendations based on the results: “Mental health service consumers’ reliance on religious faith and service attendance cannot and should not be dismissed as a symptom of their underlying psychopathology”</td>
<td>Yangarber-Hicks (2004)</td>
</tr>
<tr>
<td></td>
<td>“One purpose that religion plays in coping is that one’s faith can provide a sense of meaning and purpose that affords the individual a sense of hope for the future and a source of comfort for the present.” (p. 121)</td>
<td>Bussema &amp; Bussema (2000)</td>
</tr>
<tr>
<td>Physical activity/Leisure/Recreation</td>
<td>Physical benefits (e.g., weight loss, reduced risk of diabetes), higher quality of life and well-being, reduce symptoms of schizophrenia</td>
<td>Richardson et al. (2005)</td>
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Community Integration Principles: Rights, Roles, Responsibilities

- Community integration is a right
  - Americans with Disabilities Act (1990)
  - Supreme Court Olmstead decision (1999): unnecessary institutionalization is a form of discrimination prohibited by the ADA
  - Policy initiatives
    - President’s New freedom Initiative (2001)
Community Integration Principles: Rights, Roles, Responsibilities

• Community integration offers opportunities for participation in varied roles.
  – Employment, education, housing, civic life, family, friendships, peer support, intimate relationships, spirituality, health and wellness, leisure/recreation, finances

• Community integration promotes a sense of responsibility
  – Like everyone else, people with disabilities have a range of responsibilities, from monitoring their own health and welfare to being responsive to the needs and concerns of their communities
<table>
<thead>
<tr>
<th>Participation Less Like Everyone Else</th>
<th>Participation More Like Everyone Else</th>
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<tbody>
<tr>
<td>Institution/Agency-Based --------------Community-Based participation</td>
<td></td>
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<tr>
<td>Staff-directed participation-----------Person-directed participation</td>
<td></td>
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<tr>
<td>Separation-----------------------------Association</td>
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Community Integration Principles: Effective Strategies

- Community integration is founded on consumer choice and self-determination
- Community integration involves use of natural supports
- Community integration means access to mainstream resources
Community Integration Principles: Effective Strategies

- Shift in views about disability
  - Old paradigm: “Disability” is something inherent within an individual
  - New contextual paradigm: “Disability” results from a person-environment interaction that reduces opportunities for people to live like everyone else

- Reduce “disability” and increase opportunity by
  - Identifying, reducing, and eliminating environmental barriers
  - Identify individual needs and make individualized supports readily available
Common Environmental Barriers

- Discrimination
- Disempowerment
- Poverty
- Transportation
Common Individual Needs

• Rediscovering hopes, dreams, and desires
• Self-stigma
• Accessing community resources
• Skills training
• Personal assistance and support
Community Integration Practices

• Promote self-determination and informed choice
• Encourage use of mainstream resources
  – Greatly expands potential supports and resources available to the person
  – Increases interactions with general community
  – “Scavenger Hunt” (Bell in Menlo Park VA)
• Mobile, community-based supports (Feren in OR. VA)
• Create opportunities for reciprocal relationships and interdependence (Alternatives Inc. in MA.)
• Promote development and use of natural supports
  – Circles of supports: Bringing families and other supporters
Community Integration Practices

- **Citizenship**
  - Promote volunteering (Alternatives, Inc.)
  - Identifying volunteer opportunities
  - Full membership in civic groups (Lions Club, Knights of Columbus, Rotary, etc)

- **Religion/Spirituality**
  - Spiritual Supports Facilitator (PA)
  - Congregant helper/support network
  - Crisis planning and contract
  - Congregation education

- **Leisure/Recreation**
  - Developing partnerships with health clubs (ALTEC and Hatfield Athletic Club): Memberships and paid internships
  - Trading memberships for workshops and education on MH issues
  - Health club: On-site workout buddy (staff or member)

- **Social Roles**
  - “No Longer Lonely” – Dating, singles groups, intimacy education, speed dating
  - Parenting supports
  - Utilizing Family Resource Network

- **Housing**
  - Integrated apartments (Santa Barbara MHASP)

- **Dropin Centers as community resource centers**

- **Self-Determination**
  - Consumer councils