Life In The Community Like Everyone Else: Community Inclusion And The Essential Role Of Peers

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Disclosure and Acknowledgments

• I have no financial conflicts of interest to disclose associated with this presentation.
  • Salary support over the past year includes:
    • NIH; NIDILRR; Mental Health Partnerships (SAMHSA); Project Home (SAMHSA); PA BAS/Drexel University (ASERT/Commonwealth of PA)
  • Consulting over the past year includes
    • NASMHPD; JBS; National Council; Yellowbrick; County of San Diego; Health & Human Resources Education Center (Alameda County, CA); NC Governor’s Institute; ORE-ACT; Florida Certification Board; NYS OMH; Vocal VA (state grant)
  • I am a member of the Board of Directors of Pathways PA
  • I will be mentioning work I do with the Copeland Center that has led to paid consulting work, but I receive no payments from the Copeland Center
  • Travel support for this presentation was provided by iNAPS. No honorarium was accepted.

• Acknowledgments for this presentation
  • The contents of this presentation were primarily developed with grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (90RTCP0001-01-00 and 90RT5021-02-00) within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policies of NIDILRR/ACL/HHS, and you should not assume endorsement by the U.S. Federal Government.
Thrilled To Be Here for Many Reasons
Everything I know Comes from Peers: Long-Term Ally of Peer Support

Julian Rappaport
Community Participation: Every “Recovery” Story I Have Heard Involves Community Participation

• Employment
• School
• Housing
• Dating/marriage
• Parenting
• Leisure/recreation
• Spirituality/religion
• Civic engagement
• Friendships and social relationships
I Believe that Peers Are Essential for Promoting Community Inclusion and Participation

1) Who knows better about living in the community with lived experience than peers? – Knowledge and Skills

2) Who understands the importance of inclusion and participation more than peers? - Dedication and Passion

3) Who is changing the perspectives and ways of thinking of non-peers at all levels around the world? – Presence and Advocacy
At The End of This Keynote I Hope That...

• You have the evidence for convincing your colleagues that inclusion and participation are not just a right, and are also critical for everyone’s physical, cognitive, and mental health and wellness

• You learn some fundamentals for promoting inclusion and participation

• You have new ideas and resources for how you can promote inclusion and participation
What is Community Inclusion?

1. Being valued for one’s uniquenesses
2. Opportunity to participate like everyone else
3. Welcoming and embracing environment
Community Integration/Inclusion as a Right

• Definition: “The opportunity to live in the community, and be valued for one’s uniqueness and ability, like everyone else.” (Salzer, 2006)

• Legal and Policy Grounding
  • Americans with Disabilities Act (1990)
  • Supreme Court Olmstead decision (1999): unnecessary institutionalization is a form of discrimination prohibited by the ADA
  • President’s New freedom Initiative (2001)

Community Participation as a Medical Necessity*

International Classification of Functioning, Disability, and Health (ICF: WHO, 2002)

Health Condition (Disorder or Disease)

Body Functions and Structure

Activity (Execution of a task or action)

Participation (Mobility and Involvement in a social situation)

Personal Factors

Environmental Factors

Contextual Factors
Would, Could, and Should Participate

- People with significant mental health issues want to participate.
- Evidence-based interventions exist that promote participation (supported employment, housing, education, socialization).
- Ample evidence that participation is good for everyone, including people with serious mental illnesses.
Participation Affects Cognitive Functioning

• Physical activity: “A growing body of literature suggests that physical activity beneficially influences brain function during adulthood, particularly frontal lobe-mediated cognitive processes, such as planning, scheduling, inhibition, and working memory.”
  

• Social interaction: Social isolation associated with cognitive decline (Cacioppo & Hawkley, 2009)

• Unemployment: Eldar Shafir – Research on the science of not having enough -- “Poverty impedes cognitive function” (Science, Aug 2013)
  
  • The strain of poverty drains cognitive resources, especially as tasks become more challenging and complex
Current State of Community Participation
More People in the community…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
Fundamentals for Promoting Community Inclusion and Participation

Knowledge and Beliefs

• Fundamental #1: Community Inclusion is important
• Fundamental #2: Community Inclusion applies to everyone
• Fundamental #3: Community inclusion requires seeing ‘the person,’ not ‘the patient’
Fundamental #4: Self-Determination and Dignity of Risk are Critical

• Self-determination refers to “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 1996, p. 24).

• Dignity of risk (Perske, 1981) refers to the right to make choices that affect one’s own life even when these choices could, or do, turn out to be mistakes, allowing individuals to learn from their mistakes, along the way, like everyone else.
Fundamental #5: Multiple domains of mainstream life should be sought
Fundamental #6: Seek participation that is more like everyone else

<table>
<thead>
<tr>
<th>Participation Less Like Everyone Else</th>
<th>Participation More Like Everyone Else</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution/Agency-Based--------------</td>
<td>Community-Based participation</td>
</tr>
<tr>
<td>Staff-directed participation------------</td>
<td>Person-directed participation</td>
</tr>
<tr>
<td>Separation------------------------------</td>
<td>Association</td>
</tr>
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</table>
Fundamental #7: Use emerging support technologies, the natural supports of families and friends, and the engagement of peer supports.
Fundamentals #9-11: The Environment and Social Determinants

• Using resources available to everyone
• Understanding and addressing environmental barriers
  • Understanding social model of disability
• Creating welcoming and embracing communities
Peer Roles in Promoting Inclusion and Participation
• Temple University Collaborative has partnered with The Copeland Center and Doors to Well-Being on a Community Inclusion Peer Facilitator Certification Initiative

• 3-day experiential course

1. Understanding one’s own community inclusion and participation
2. utilize tools for identifying, addressing and improving policy and organizational changes to improve community inclusion outcomes;
3. apply 1:1 facilitation skills in supporting a peer in recovery to increase their role and meaning in the community of their choosing;
4. expand their community connections and supportive networks to promote community wellness.

I have an unpaid role with D2W as a policy and evaluation adviser
Address Knowledge and Beliefs

- People need to be made aware of the importance of inclusion and participation on health and wellness
- Appreciate that we generally cannot predict readiness for participation beyond being in an acute state and motivation
- Need to alter our perceptions about people with SMI
  - Mental health professionals have similar attitudes and beliefs about individuals with SMI as the general population: “nearly three quarters of the relevant publications report that beliefs of mental healthcare providers do not differ from those of the population, or are even more negative” (Schulze, 2007, p. 142).
  - Research on Pygmalion effect
- Strategies for Helping Us Tell “John the Person” Stories
  - Authentic engagement of peer specialists
  - Peer engagement in co-developing and implementing services
  - Stigma-busting campaigns within our mental health services (Joyce Bell labeling exercise)
  - More consumer speakers “in-house”
  - Providers learning to tell our recovery and inclusion stories about people we work with
Promote and Protect Self-Determination and Dignity of Risk

• Use approaches that facilitate self-determination and address risk head-on rather than opposing risk outright
  • WRAP; Develop “personal medicines”; SDC; Psychiatric Advanced Directives; Shared Decision-Making
  • Doing “with” rather than “for”
Addressing Prejudice and Discrimination

- Increase public awareness and advocacy
  - Systems and program advocacy
  - Speakers bureaus
- Address self/internalized stigma
  - Combat years of being told you wouldn’t, couldn’t, or shouldn’t participate
Supported Community Inclusion and Participation Intervention

• Support people in identifying their inclusion and participation interests
  • TUCP
• Identify individual needs and environmental barriers that limit participation
• Support the development of a plan to address these issues
• Increase knowledge and access to mainstream resources
• One particular program I really like
  • Community Recovery Connections Program (Bedford VAMC)
Natural Support Interventions

• Building and utilizing natural supports
  • COMPEER
  • Club 21 (Alternatives, Inc.)
  • Circles of Support
Peers Can Be the Advocates for Change in Programs and Organizations

Jump-Starting Community Living and Participation

A Toolkit for Promoting Inclusion in Community Life

Richard C. Baron, MA
Challenges in Promoting Inclusion: More Comfort with Some Topics Rather than Others?
<table>
<thead>
<tr>
<th>Please tell us how often you support your peers in...</th>
<th>Mean Score 1 = “Never” 5 = “Always”</th>
<th>Type of Support</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Intimacy Supports</td>
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<td>transportation</td>
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<tr>
<td>citizenship (e.g., voting, volunteering, advocacy)</td>
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<td>education</td>
<td>3.16</td>
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<tr>
<td>employment</td>
<td>2.94</td>
<td>Career Supports</td>
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<td>developing WRAP plans</td>
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<td>WRAP/PADS</td>
</tr>
<tr>
<td>developing psychiatric advanced directives</td>
<td>2.27</td>
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Family Resources

• Families Healing Together – A recovery-oriented family psychoeducation program
• Promote family-based leisure
Religion Resources
Intimacy and Sexuality
Parenting with a Mental Illness: Programs and Resources

Peers in Practice: Supporting Parents with Mental Health Issues

By Fred McClaran, MS, CPS, WRAP Facilitator

Managing one’s own recovery can be challenging enough at times, but the additional challenges of parenting can be daunting, even for those who have no mental health diagnoses. Studies of individuals with mental health issues have shown a large number of parents report difficulties managing both their own mental illness and the challenges of parenting. Certified Peer Specialists can play a unique role in supporting clients with the needs and challenges of parenting. Peer specialists are trained and encouraged to be open with their clients about their own behavioral health challenges and can use their own parent experiences to provide support.

Ways peer specialists can support clients with parenting needs:

- Help strengthen their parenting skills by sharing personal experiences, providing access to parenting resources, and listening to concerns.
- Reminding clients that a client’s role as a parent may be motivational to exercise in one’s personal recovery; this dedication to self may also be a role model for children.
- Use role modeling and role play exercises to practice communication techniques, establishing healthy discipline, and identifying appropriate boundaries for children.
- Help & support in the areas of discipline, boundaries, & effective communication, including through role modeling & role play exercises.
- Supporting clients with their own personal emotional and physical health, including addressing how self-care is an essential part of good parenting.
- Educate, and support ways clients can help their child cope with stress, school, and peer pressure.
- Children have active schedules; Peers can support the parent’s involvement in diverse activities in the community, including school, religion, sports, clubs, and other important areas of participation.
- Provide other resources and support such as NAMI (National Alliance on Mental Illness) and other organizations and groups that can support them with both parenting and their own personal recovery.
- Much importantly, assure them that they are not alone. And as a peer specialist, you are there for them to help and support them as parents, as well as with their own personal recovery.

This document was created and updated by the National Alliance on Mental Illness (NAMI) and the National Alliance on Mental Illness (NAMI) and other organizations and groups that can support them with both parenting and their own personal recovery.

Supporting Parents with Psychiatric Disabilities: A Model Reunion Statute

Developed by: Jeannette Scott, J.D.

Key Contributors: Jennifer Mithoefer, Esq. &
Im Burman, Esq. of the Reunion Center for Mental Health Law

The content of this model statute was developed under a grant to the Division of Psychiatry from the Department of Education, IDEIA grants number #H156B00020 (Christ, Ph.D.). However, these contents do not necessarily represent the policy of the Department of Education, and any opinion expressed herein is that of the author. Specific information is given to William Hackett, School of Law Professor Richard Fuller, Calderia attorney, Jonathan J. Eames, Dr. Peter Jackson of the University of California, School of Advanced Studies in Child Welfare; and Elyse Koger, from the University of Pennsylvania’s Collaborative on Community Integration, for their opinions and comments.

Temple University Collaborative on Community Integration is a Region X Research & Training Center Promoting Community Integration of Individuals with Psychiatric Disabilities, funded by the National Institute on Disability and Rehabilitation Research (NIDRR). For more information, please visit www.tupenn.org.
Challenges in Promoting Community Inclusion

• Group events are seductive, but do they lead to full inclusion?
  • Strong belief in the benefits of getting people out to a group event, but I am not sure how beneficial it is in the long-term (or even short term)
    • Concern that we become overly dependent on group events and do not move to individualized inclusion supports
  • Group events are easier and make us feel good about doing something, but it is not really inclusion
    • Gets big numbers of participants, are fun, and makes us feel good
• Concerns about readiness or capabilities
• Output incentives: We can point to how many people we are supporting and how many events we put together, but long-term inclusion is not happening
• Promoting inclusion is hard, and requires really good supervision and teamwork that focuses on individual situations
Thank You!!

Feel free to contact me at

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Checkout our website:

www.tucollaborative.org