Community Inclusion and Money Follows the Person

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Temple University Collaborative
On Community Inclusion of Individuals with Psychiatric Disabilities

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College of Public Health

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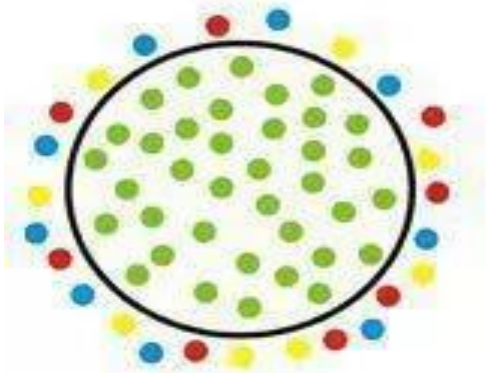
Community Participation

- Employment
- School
- Housing
- Dating/marriage
- Parenting
- Leisure/recreation
- Spirituality/religion
- Civic engagement
- Friendships and social relationships

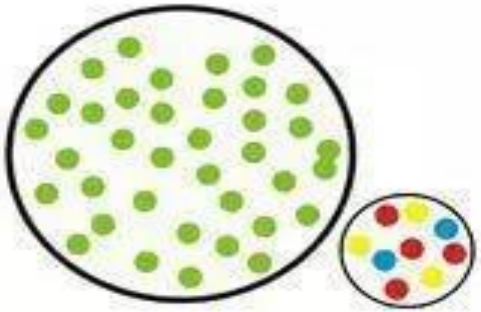
What is Community Inclusion?

Inclusion

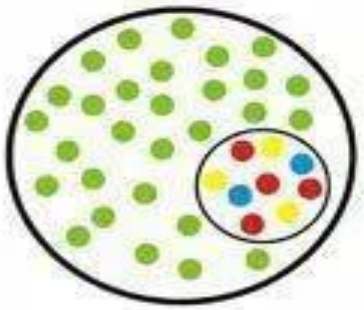
1. Being valued for one's uniquenesses
2. Opportunity to participate like everyone else
3. Welcoming and embracing environment



Exclusion



Segregation



Integration

https://www.thinkinclusive.us/inclusion-exclusion-segregation-integration-different/

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)
  - President’s New Freedom Commission Report (2003)

Salzer, M.S. (2006). Introduction. In M.S. Salzer (ed.), Psychiatric Rehabilitation Skills in Practice: A CPRP Preparation and Skills Workbook. Columbia, MD.: United States Psychiatric Rehabilitation Association.

Community Participation as a Medical Necessity*

*Salzer, M.S. & Baron, R.C. (2016). Well Together – A blueprint for community inclusion: fundamental concepts, theoretical frameworks and evidence. Published by Wellways Australia Limited, Melbourne, Australia. Available at http://tucollaborative.org/wp-content/uploads/2017/05/Wellways-Well-Together.pdf

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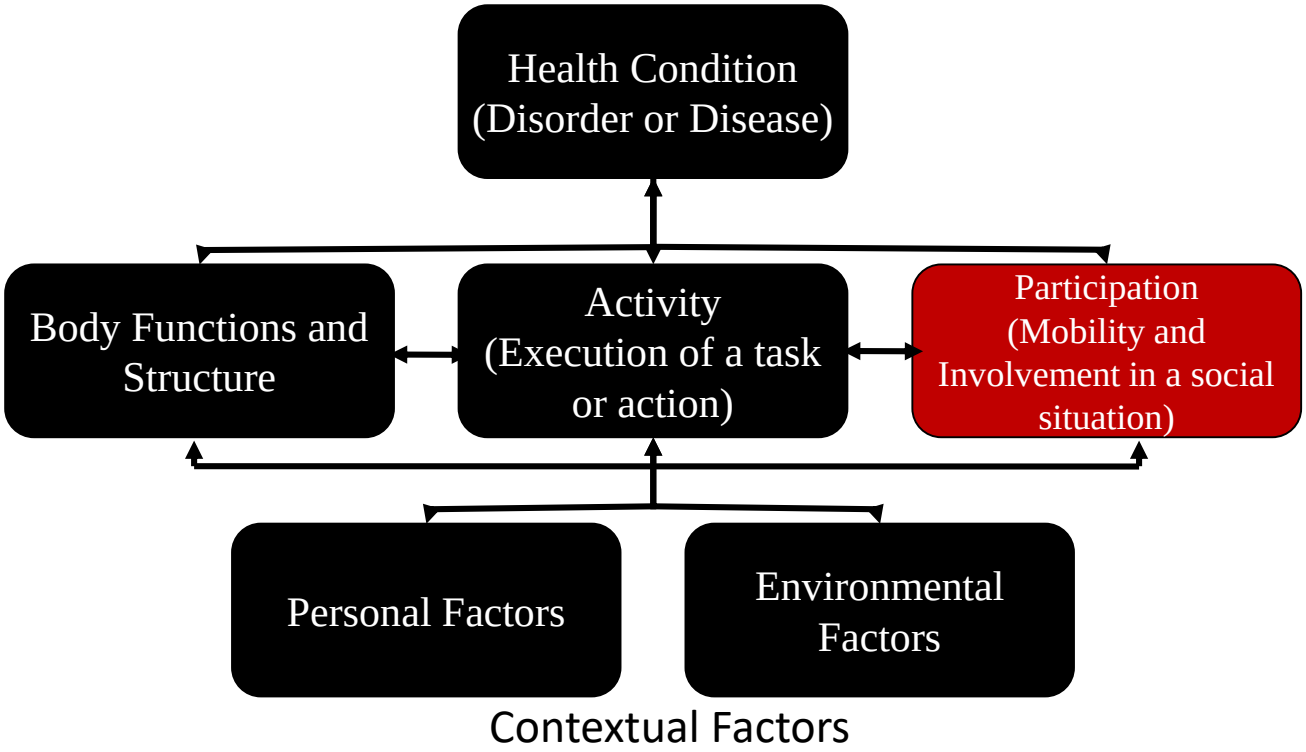
International Classification of Functioning, Disability, and Health (ICF: WHO, 2002)



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."
  - Ratey, J. J., & Loehr, J. E. (2011). The positive impact of physical activity on cognition during adulthood: a review of underlying mechanisms, evidence and recommendations. Rev Neurosci, 22(2), 171-185. doi: 10.1515/rns.2011.017
- 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

Fundamentals for Promoting Community Inclusion and Participation

Salzer, M.S. & Baron, R.C. (2016). Well Together – A blueprint for community inclusion: fundamental concepts, theoretical frameworks and evidence. Published by Wellways Australia Limited, Melbourne, Australia. Available at https://media.wellways.org/inline-files/Well%20Together_2%20May%202016_Final_Web_0.pdf

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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’

Implications - Training

- Staff need to be made aware of the importance of inclusion and participation on health and wellness
- Become more aware about long-term outcomes on recovery
  - Bellak (2006) offered two perspectives
    - Consumer-oriented perspective: Living a satisfying, fulfilling, and hopeful life with or without symptoms of one's illness -- Numerous studies show that people with serious mental illnesses, even when symptomatic to varying degrees, can work, go to school, have friends, be parents, benefit from peer support, vote, exercise, and have hopeful, meaningful lives
    - Medically-oriented perspective (a.k.a. remission-oriented): focus on symptom reduction; improved functioning; decreased hospitalizations – Numerous studies of residents of long-term psychiatric hospitals have found that at least 50% of those diagnosed with schizophrenia at one time point when they were in the hospital were deemed to be "recovered" when assessed 20-40 years later
      - No evident impairments
      - taking meds. with few symptoms
      - not taking meds.
      - not hospitalized for at least 5 years

Implications - Training

- 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

Fundamental #4: Self-Determination and Dignity of Risk are Critical

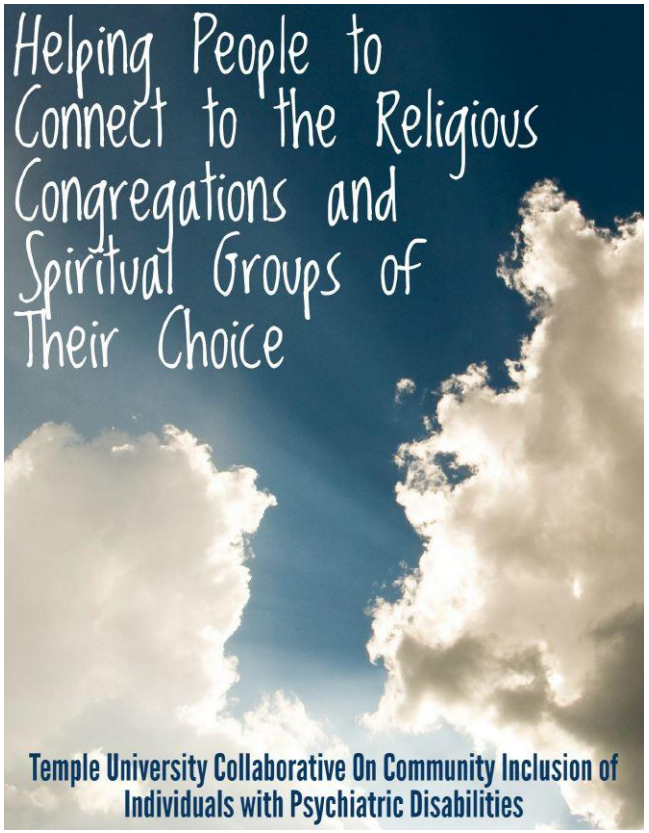
- Self-determination refers to "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996, p. 24).
- Dignity of risk (Perske, 1981) refers to the right to make choices that affect 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 #4: Self-Determination and Dignity of Risk Should Be Protected

- 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"
  - Managing risk - http://tucollaborative.org/pdfs/Toolkits_Monographs_Guidebooks/community_inclusion/Managing_Risk_in_CI.pdf

Fundamental #5: Multiple domains of mainstream life should be sought

Religion Resources



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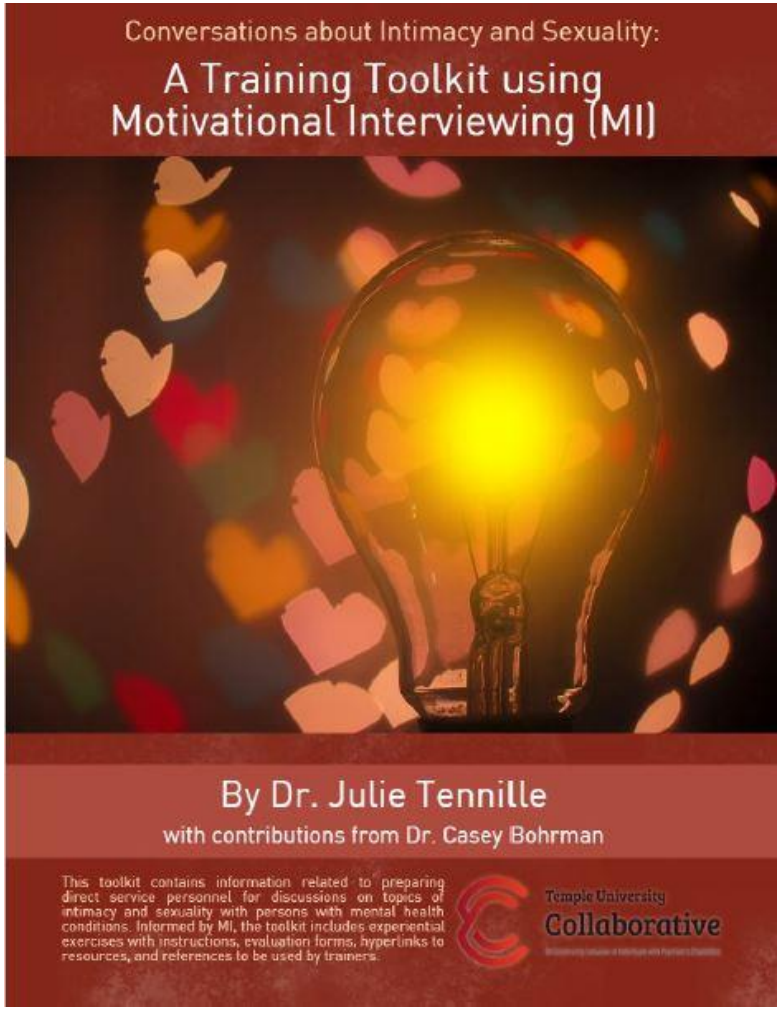
Intimacy and Sexuality



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Parenting

UPenn Collaborative on Community Integration

Parenting with a Mental Illness:
Programs and Resources

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Peers in Practice: Supporting Parents with Mental Health Issues

By Fred McLaren, 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 diagnosis. 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 parenting experience 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 one's role as a parent may be motivation to continue 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, emphasizing how self-care is an essential part of good parenting.
- Help, 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.
- Most 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 developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number #90RT5021-02-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this document do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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Judge David L. Bazelon Center for Mental Health Law

Supporting Parents with Psychiatric Disabilities: A Model Reunification Statute

Developed by: Jeniece Scott, J.D.

Key Contributions by: Jennifer Mathis, Esq. &
Ira Burnim, Esq. of the Bazelon Center for Mental Health Law

The contents of this model statute were developed under a grant to the University of Pennsylvania from the Department of Education, NIDRR grant number H133B030029 (Salzer, PI). However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government. Special recognition is given to Villanova University School of Law Professor Richard Redding, disability attorney Stephen F. Gold, Dr. Traci LaLiberte of the University of Minnesota's Center for Advanced Studies in Child Welfare, and Katy Kaplan from the University of Pennsylvania's Collaborative on Community Integration, for their guidance and comments.

The UPenn Collaborative on Community Integration is A Rehabilitation 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 us at: www.upennrtc.org

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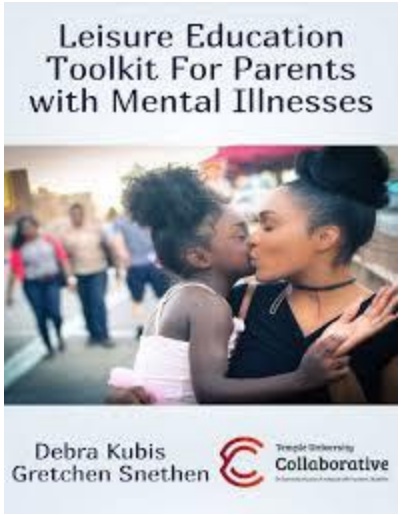
Fundamental #6: Seek participation that is more like everyone else

Participation Less Like Everyone Else	Participation More Like Everyone Else
Institution/Agency-Based	Community-Based participation
Staff-directed participation	Person-directed participation
Separation	Association

Fundamental #7: Use emerging support technologies, the natural supports of families and friends, and the engagement of peer supports

Fundamental #8: Providing support to family and other natural supports promotes community integration

- Families Healing Together – A recovery-oriented family psychoeducation program
- Promote family-based leisure



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Fundamentals #9-11: The Environment and Social Determinants

- Using community-based resources that are available to everyone
- Understanding and addressing environmental barriers
  - Understanding social model of disability
- Creating welcoming and embracing communities

Self-Direction and Inclusion (The CRIF Demonstration Project)

- Magellan Health Services
- Office of Behavioral Health, Delaware County, Pennsylvania (In coordination with PA OMHSAS)
- Temple University Collaborative on Community Inclusion of People with Psychiatric Disabilities
- Mental Health Association of Southeastern Pennsylvania

PA-DELCO SDC

- RCT funded by NIDRR
- Inclusion criteria
  - Delaware County Resident
  - Member of Health Choices, Magellan Behavioral Health
  - Schizophrenia-spectrum (295.XX) or affective disorder (296.XX)
  - 50th – 90th%-ile utilizer of services ($7,000 - ~$20,000 ambulatory services only in previous 2 years)
  - No hospitalizations within the past 6 months
- 120 total in study: 60 in SAU, 60 in SDC

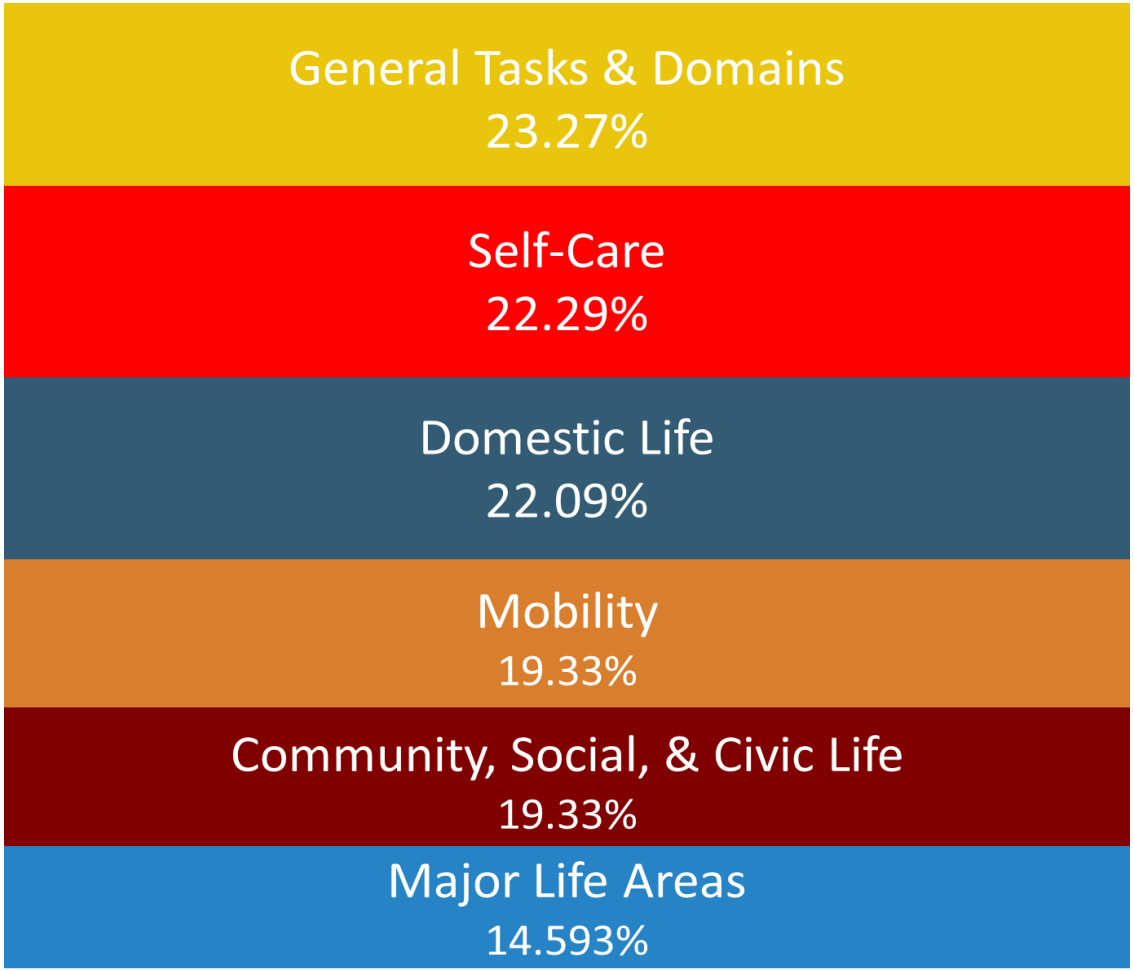
PA-DELCO SDC Model

- CRIF Program: Consumer Recovery Investment Funds
  - Develop planned budget based on previous two-year ambulatory expenditures
  - CPS Recovery coach assists in this process
    - Peer support plus budgeting coaching
    - Exploring dreams to develop goals
    - Reviewing past 24 month utilization with peer
    - Setting budget from goal activities
    - Requesting authorization for purchases
    - Authorization approved by Magellan Health Services
    - Monthly check-ins with Recovery Coach, or as determined by Participant
    - Recovery coach tracks expenditures
  - Freedom Funds were not capped and had no real affect on traditional service use

Asks Analysis From an ICF Standpoint (Snethen et al., 2016)

- Asks Process: Each program participant worked with their recovery coach to identify their mental health, recovery, and wellness goals and then identify traditional services, and out-of-plan services (i.e., Asks), to help them meet these goals. Each service required a justification of its "medical necessity" that was forwarded to Magellan for approval.
- Method: Asks from all participants who made such requests, along with their justification that was sent to Magellan were gathered from the program's records.
- Coding System: Asks were coded using the codes from the Activities and Participation section of the ICF. Codes were drawn from the following chapters: General Tasks; Self-Care; Domestic Life; Mobility; Community, Social, and Civic Live; and Major Life Areas.
- Coding Process: Coders reviewed the specific item or service identified and the recovery justification to determine the specific domain of participation facilitated. Asks were coded by 2 primary coders who separated asks into 6 parent codes and 42 total specific codes. When a discrepancy arose a third coder independently coded the ask. A final decision was made by 2 additional coders if there was no match for the codes. Most asks received only one code, but some did require two codes.
- Statistics: Descriptive statistics were used to represent the primary areas of participation facilitated by the asks. The coded asks were divided by the total number of asks (N=507).

Asks and %'s By Category



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Specific Asks and %'s by Category

General Tasks

ICF Code	Definition	Percentage
2301	Managing Daily Routine	3.94
2400	Handling Responsibilities	3.75
2401	Handling Stress	8.09
2402	Handling Crisis	0.39
2403	Handling Depression	4.93
2404	Handling Anxiety	2.17
Example responses: Driving lessons; past-due electric bill; Verizon bill; groceries; entertainment; clothes; relocation costs		

Self-Care

ICF Code	Definition	Percentage
5200	Caring for Body Parts	0.79
5400	Dressing	1.58
5500	Eating	1.18
5701	Managing Diet and Fitness	11.05
5980	Maintaining One's Health	7.30
5980	Self-care other specified	0.39
Example responses: Curves membership; Nutritious food; Boston Market and Colonial Kitchen; Eye Exam		

Domestic Life

ICF Code	Definition	Percentage
6100	Acquisition of a Place to Live	7.10
6200	Acquisition of Goods and Services	4.73
6300	Preparation of Meals	0.79
6500	Caring for Household Objects	0.20
6501	Maintaining Dwelling & Furnishings	6.11
6503	Maintaining Vehicles	2.96
6600	Assisting Others	0.20
Example responses: Bedding; Utility Bills; Moving Expenses; Home Repairs; Insurance; Baby shower and baby supplies; groceries, entertainment and clothes		

Specific Asks and %'s by Category

Mobility

ICF Code	Definition	Percentage
4000	Movement other	1.78
4500	Walking	0.20
4701	Using Private Motorized Transportation	6.11
4702	Using Public Transportation	11.24
SEPTA monthly pass; Tokens Shopping, Errands, Appointments; Gym--Travel Costs; Sneakers & Shoes for Walking		

Major Life Areas

ICF Code	Definition	Percentage
8100	Informal Education	0.39
8200	School Education	1.18
8250	Vocational Education	0.39
8300	Higher Education	2.37
8450	Acquiring a Job	6.71
8451	Maintaining a Job	1.58
8550	No remunerative	1.97
Example responses: Computer classes; GED class; Microsoft manual; Books; Laptop; Clothing; hearing aid hearing exam; Tuberculosis test		

Community, Social, and Civic Life

ICF Code	Definition	Percentage
9100	Informal Associations	0.20
9102	Ceremonies	0.20
9200	Play	0.39
9201	Sports	1.78
9202	Arts and Cultures	2.96
9203	Crafts	0.59
9204	Hobbies	0.20
9205	Socializing	4.93
9208	Recreation & Leisure, other specified entertainment	5.13
9210	Recreation & Leisure, other specified thinking, contemplation	0.20
9300	Organized Religion	1.58
9301	Spirituality	0.59
Example responses: Graduation fees; Six Flags; Women's group retreat; YMCA membership; New National Baptist Hymnal; Simple Abundance Companion; Large-Print Bible		

SDC Promotes Self-Determination and Choice

Theme	Subtheme	Description	Example
Competence	Access to financial resources (cash funds)	Participants expressed that because of the availability of cash funds as part of the SDC intervention, they had the means to access more goods/services to achieve desired goals.	"I now crochet. I never would have had the money to buy materials before."
	Access to non-traditional goods or services	Participants said that they had the ability to access options other than those traditionally offered because of the intervention.	"I can think outside the box in regards to what will make me more independent."
	Knowledge and Information	Participants described learning more about goods/services available or being provided with information in order to make decisions about or access good/services.	"They gave me a list of places to go for activities and volunteering."
Autonomy	Offered choices	Participants said that they had more choices because they were offered choices.	"Unlike the traditional care I used to receive they actually offered things to me, even if I didn't take it."
	Opportunities for autonomous decision-making	Participants indicated that they had the ability to make choices by themselves for themselves.	"I have a say in what I want to do in terms of services..."
Relatedness	Emotional support	Participants said that the recovery coach empathized, listened, or accompanied them to an activity in order to provide moral support.	"I have a person to talk to." "I go to meetings with the recovery coach. I'm too scared doing this on my own."
	Peer support	Participants commented about how they had greater choice because of the unique benefits of working with a recovery coach with lived experience of a mental health condition.	"[Recovery coach] knew a lot more resources than someone who wasn't in recovery."
Miscellaneous Support	NA	Participants described being supported to make choices, but did not specify how.	"They gave me support in ways other places didn't..."

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Thomas, E., Zisman-Ilani, Y., & Salzer, M.S. (under review). Self-determination and choice in the context of mental health services: qualitative insights from a study of self-directed care.

12-Month Findings: "Do you feel like being involved in the CRIF program has facilitated your recovery and mental health?"

- Yes, helped to make me more independent.
- Yes, helping to get things insurance wouldn't normally cover like computer & GED classes.
- Yes. Because it contains everything a consumer would need to move forward. Shame on the person who doesn't take part in the program.
- Yes. Very supportive and helped me to get out the feeling of loss and hopelessness.
- Yes, helped me to take back control of my life.
- Yes. (CRIF staffperson name) made me realize for the first time that I had mental health issues. Also, computer I received from SDC helps with my anxiety.
- Yes, a majority of my stress and depression came from not being able to provide for my kids so when I was able to finally, it was such a relief
- Yes; without the program I would've been furniture-less

12-Month Findings: "Do you feel like being involved in the CRIF program has facilitated your recovery and mental health?"

- Yes, I wouldn't have help, wouldn't be able to do what I need for my mental health
- Yes, they have taught me to be more assertive when I am not happy with services.
- Yes. I have learned to put de-stressing tools into action. Two of my medications have been lowered.
- Yes, it helped me overcome my symptoms.
- Yes. It's helped to deal with bills relieving stress getting where I need to go, and helping with taking care of my mother.
- Yes, it has helped, I was on 4 medications but now I am only taking 2.
- Yes, I am not stuck in one set mode-when they visit or when I go there. I people to talk to that will give me their view points on what I am dealing with.
- Yes, because I have choices.

"Do you feel like being involved in the CRIF program has facilitated your recovery and mental health?"

- Yes, helped me be more confident, don't feel alone anymore, don't feel closed in, I can go out now instead of sitting stressing about things.
- It has helped. It makes me look toward the things n life that make me happy and satisfied.
- Yes; more open and socializing. More responsible and knowledgeable about my triggers.
- Yes, usually I'm isolated and this brought me out of my shell.
- Yes, allowed me to feel better about myself than I normally do.
- Very much so; makes me get up in the morning and enjoy the day.
- Yes; it gives me an opportunity to assist in the mater.
- Yes, allowed me to do the things I need; like bus passes & someone to talk to. Allowed me to throw a baby shower for my niece.

Thank You!!

Feel free to contact me at
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www.tucollaborative.org

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