A life in the community like everyone else:
Evidence and innovation

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A Life in the Community: John the Person (Fundamental #3: Seeing 'the person,' not 'the patient')

John lived in his country home with his parents and three older siblings. As the youngest child, with three older sisters, he was the center of his family's attention for many years and enjoyed being the focus of their lives. He was not at all thrilled with the idea of leaving this nurturing environment to enter school, where other children often made fun of him and teased him, but he did! His high school years weren't especially enjoyable (especially compared to his beginning life experiences within his family), so he was excited about the opportunity to begin working at the local McDonald's after graduation. John is not very interested in talking about the time of high school graduation until now, saying that it has been a very difficult struggle… one in which he watched both of his parents die of cancer within 2 years of each other, and his other three sisters become further distant in his life. He talks briefly about receiving a dx. of schizophrenia, the many doctors/counselors and hospitals, all of which had different labels and treatments for the problems he kept finding himself in… but he prefers now to focus on his new, one-room apt. that he's just moved to… and the fact that he is the short-order cook at the local Friendly's (15 hrs/wk). John thinks about asking, Mary, a waitress on a date… going to his sister's home for a Memorial Day picnic, and saving enough money to buy a cassette player. John is a 38 yr. old man who dreams about finding a girlfriend, working more hours, managing his finances, seeing his sisters more, and keeping his current apartment.

Salzer, M.S., & Baron, R.C. (2015). Who is John?: Community integration as a paradigm for transformative change in community mental health. In G. Nelson, B. Kloos, and J. Ornelas (Eds.). Community Psychology and Community Mental Health: Towards Transformative Change. New York: Oxford University Press.

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"People don't need more referrals to mental health services, they need referrals to life and community"

(Rapp, 1996)

Community Inclusion as a Societal Commitment

1. Ensure that all individuals have an equal opportunity to fully participate in the community
   A. A right
      i. "Convention on the Rights of Persons with Disabilities" (UN Convention, 2006). Signed by Australia (Not U.S.)
      ii. Many countries, including the U.S., do have policies stating that community integration/inclusion is a right of people with disabilities

2. Establish communities that <u>actively seek out</u> and <u>welcome the participation</u> of everyone, <u>valuing</u> each individual's <u>uniqueness</u> and potential <u>contribution</u>

Fundamental #1: Community inclusion is important – Current state of inclusion

- 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

Fundamental #1: Community inclusion is important

- ## Would participate
  - Not doing things that are important to them
- ## Could participate
  - Evidence that with supports participation is possible
- ## Should participate
  - Participation is good for everyone (positive psychology)
  - Participation is good for people with mental illnesses
  - Participation is good for cognitive functioning
    - Physical activity and neurotrophic factors
    - Loneliness and cognitive functioning
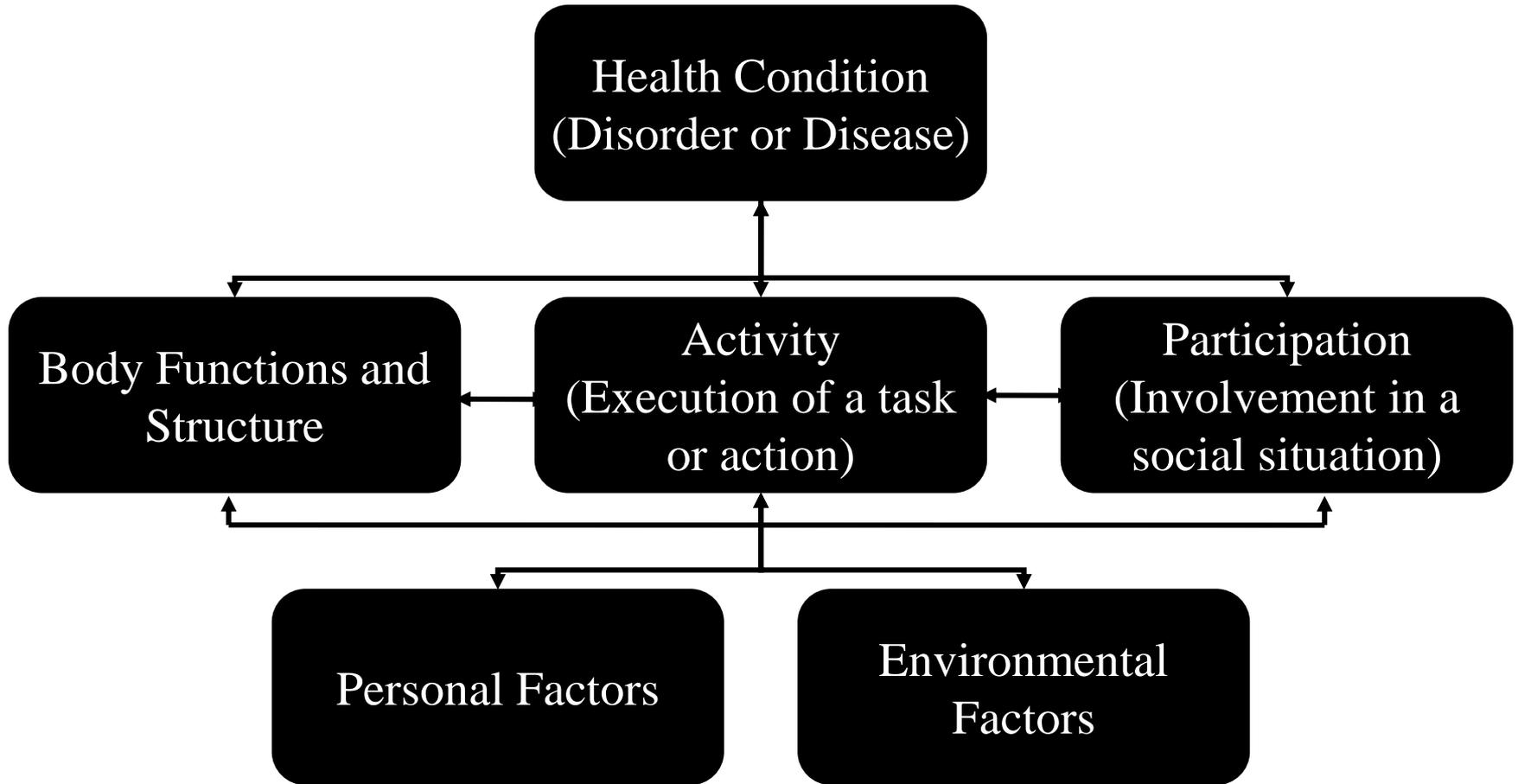   - Poverty and cognitive functioning

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People are NOT Doing what they want to do
Salzer et al. (2014)

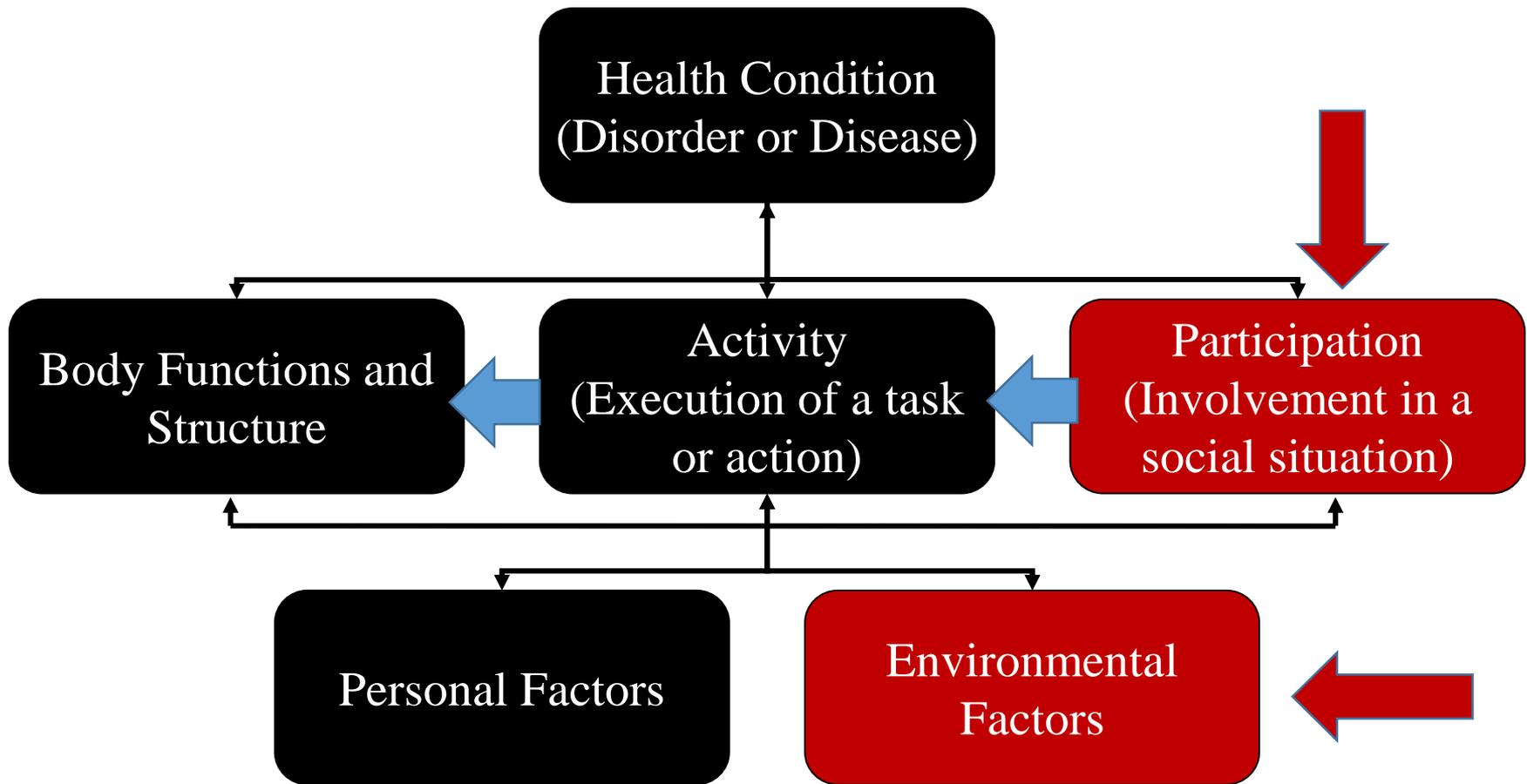|	Importance Yes		Sufficiency Less than you want	
	N	%	N	%
Go shopping at grocery store?	114	96	32	28
Go to a restaurant of coffee shop?	81	68	38	47
Go to a church, synagogue, or place of worship?	90	78	53	59
Go to a movie?	67	56	47	70
Go to a park or recreation center?	84	72	40	48
Go to a theater of cultural event?	68	58	46	69
Go to a zoo, botanical garden, or museum?	60	52	43	72
Go to run errands?	105	88	19	18
Go to a library?	80	67	46	58
Go to watch a sports event?	65	55	41	63
Go to a gym?	85	71	56	66
Go to a barber shop, beauty salon, nail salon, spa?	91	76	44	48
Use public transportation?	109	92	20	18
Go to a 12-step grp for mental health issues?	78	66	28	36
Go to a 12-step grp for substance use problems?	48	40	15	31
Go to another type of support group?	43	36	16	37
Go to a consumer-run organization?	50	42	30	60
Go to a social group in the community?	59	50	38	64
Work for pay?	83	71	54	65
Go to school to earn a degree or certificate?	75	63	51	68
Take a class for leisure or life skills?	59	50	38	64
Participate in volunteer activities?	81	68	34	42
Get together in the community or attend an event with family or friends?	85	72	41	48
Entertain family or friends in your home or visit family or friends?	95	81	50	53
Go to a community fair, community event or activity?	72	61	41	57
Go to or participate in civic or political activities or organizations?	53	45	36	69

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
(Involvement in a social situation)

Personal Factors

Environmental Factors

Contextual Factors

Promoting Participation to Promote Health

Fundamental #7: Community Inclusion is strengthened by supports

Community Inclusion Supports

- Evidence-Based Practice
  - Supported housing
  - Supported employment

- Emerging Practices
  - Supported education
  - Supported socialization
  - Supported leisure/recreation
 - Consumer/peer-delivered supports

Core Components of Supports Technology

1) Rapid – Participation-oriented supports begin as soon as an individual expresses interest in a particular area
   a. No readiness requirements
   b. No requirement to address body/structure or ADLs impairments
2) Mainstream – Participation occurs in "normal," non-segregated settings
3) Choice/Self-Determination - each individual is given a choice, and options, with regard to what they do and where they do it
4) Long-term - supports are offered as long as they are needed and desired to sustain participation
5) Integrated - Supports are delivered in partnership with other treatments/services to the degree desired by the individual.

Natural supports

- Building social networks and capital
    - COMPEER
    - Anglicare Mental Health Project
    - "21 club" (Alternatives, Inc. in central MA.)
- Circles of Support

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Mutual Aid As Old As Time…and Cross Species
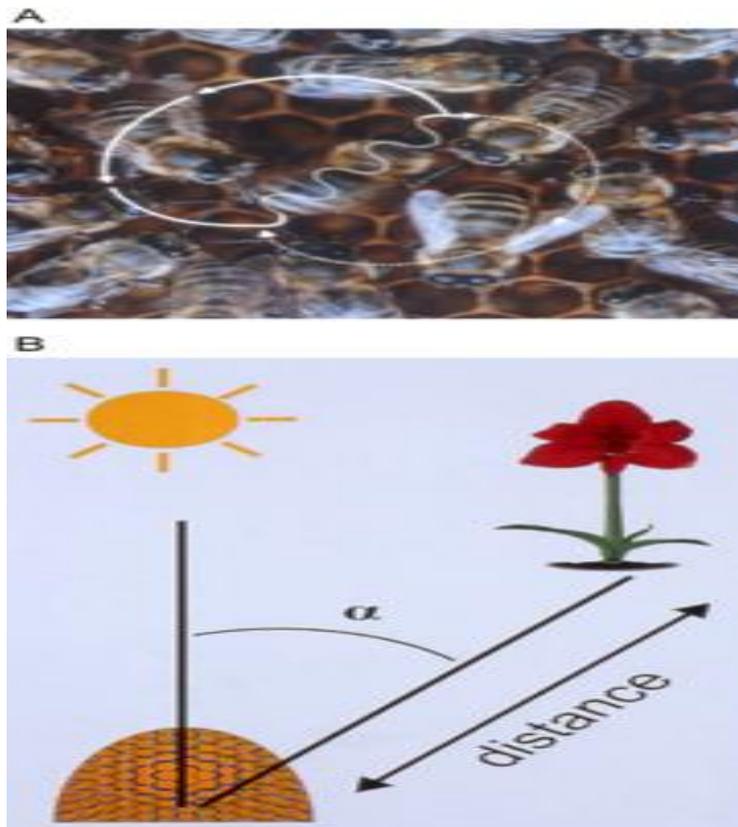
Honey Bee Waggle Dance

Theoretical Underpinnings of Peer Support (Salzer & MHASP Best Practices Team, 2002)

Theory	Description
Social Learning Theory (Bandura)	Behavior change is more likely when modeling is provided by peers than non-peers. Peers model coping and health-enhancing behaviors. Peers enhance self-efficacy that one can change behavior.
Social Support Theories	Social support enhances access to instrumental, psychological, and social resources through 5 types of support: Emotional (someone to confide in, provides esteem, reassurance, attachment and intimacy) Instrumental (services, money, transportation) Informational (advice/guidance, help with problem-solving and evaluation of behavior and alternative actions) Companionship (belonging, socializing, feeling connected to others) Validation (feedback, social comparison).
Experiential Knowledge (Borkman, 1999)	Personal experience with a phenomenon (e.g., illness) leads to an understanding and knowledge base that is unique and valuable compared to knowledge acquired through research and observation (practice) Experiential knowledge leads to different policy and intervention approaches
Helper-Therapy Principle (Riessman, 1965; Skovholt, 1974)	Helping others is beneficial through: 1) Increased sense of interpersonal competence as a result of making an impact on another's life; 2) Development of a sense of equality in giving and taking between himself or herself and others 3) Helper gains new personally relevant knowledge while helping 4) Helper receives social approval from the person they help and others.

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Salzer, M.S., & Mental Health Association of Southeastern Pennsylvania Best Practices Team (2002). Consumer-Delivered Services as a Best Practice in Mental Health Care and the Development of Practice Guidelines. Psychiatric Rehabilitation Skills, 6, 355-382.

Mental Health Peer Specialists
States where Medicaid pays for them

In 31 states, Medicaid pays for licensed peer specialists, counselors recovering from severe mental illness or substance addiction who are trained to help others with similar conditions.

■ Medicaid pays

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http://www.pewtrusts.org/~/media/legacy/uploadedimages/pcs_assets/stateline_photos/2013/09/0911topstoryvizpng.png

Challenges with the Peer Workforce in the U.S.

- Agencies and supervisors have little understanding of the peer support/mutual aid ethos

- Job roles for peers are not consistent with their skill set and lived experience

- "Peer support" is poorly defined as are peer workforce activities

Peers as "Vessels of Hope" For Living a Satisfying and Fulfilling Life

- Address inclusion areas where other providers may be uncomfortable (e.g., dating) or have less skills/knowledge
- Re-Ignite, renew, and re-energize hopes, dreams, and desires
  - Sharing personal stories
  - Dreams exercises
  - Asking about what is important and what one wants to do more of
  - Support movement toward community integration without questioning (Fundamental #2: Community Inclusion applies to everyone who experiences a disability)

Supports Through Technology

- Internet peer support
  - Kaplan, K., Salzer, M.S., Solomon, P., Brusilovskiy, E., & Cousounis, P. (2011). Internet peer support for individuals with psychiatric disabilities: A randomized controlled trial. Social Science & Medicine, 72, 54-62.

- Parental training
  - Kaplan, K., Solomon, P., Salzer, M.S., & Brusilovskiy, E. (2014). Assessing an Internet-based parenting intervention for mothers with a serious mental illness: A randomized controlled trial. Psychiatric Rehabilitation Journal, 37(3), 222-231. Doi: 10.1037/prj000080.

- Distance supported education

- GPS, accelerometers, etc. to assess mobility, physical activity, and community participation

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Fundamental #4: Self-determination and dignity of risk are central to community inclusion

Control and Choice: Self-Determination and Dignity of Risk

- Self-determination: "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.

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Self-Determination Models and Evidence

- Consumer-operated services: An EBP (http://store.samhsa.gov/shin/content//SMA11-4633CD-DVD/TheEvidence-COSP.pdf)

- WRAP: RCT study of WRAP showed it is associated with decreased symptoms and enhanced hope and QOL (Cook et al, 2011)
  - Just designated as an EBP by NREPP

- Psychiatric Advanced Directives
  - Associated with greater adherence (Swanson et al, 2010)
  - Fewer involuntary commitments (Swanson et al., 2008)

- Shared decision-making
  - More satisfied with the care planning process and had better recall of the care plan (Woltmann et al., 2011)

Self-Directed Care: "Personalized Medicine" (Deegan, 2007)

- "Personal medicine": self-taught, nonpharmaceutical strategies that persons with mental illnesses use, often in combination with psychiatric medication, to advance their recovery and improve their lives.
  - Example: a man with bipolar disorder who used math problems to help himself get to sleep and thus avoid a manic episode

- "There seem to be as many types of personal medicine as there are individuals: fishing, parenting, repairing airplanes, walking, diet, caring for pets, friendship, driving..." (Deegan, 2007, p. 65).

Deegan, P. E. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. Psychiatric Rehabilitation Journal, 31(1): 62-69.

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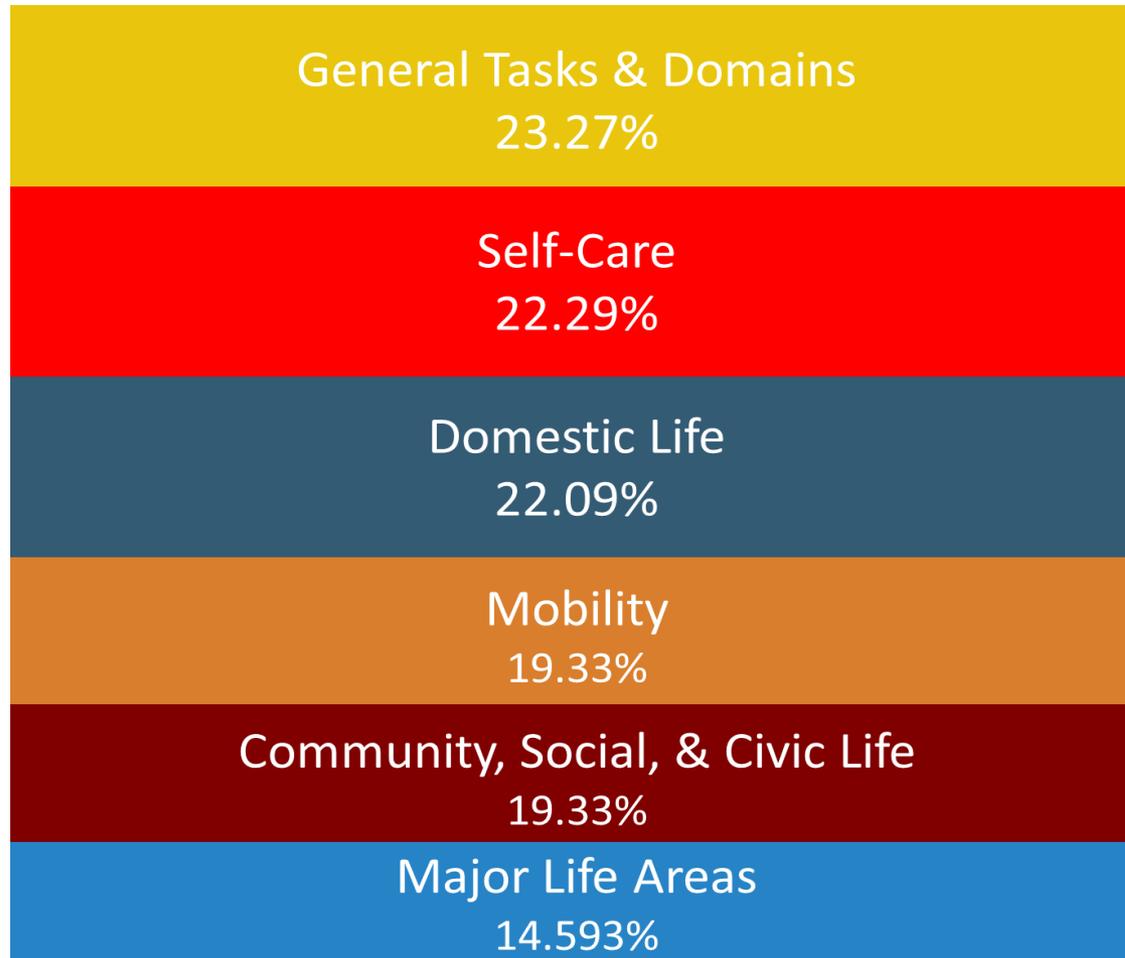# Pennsylvania-Delaware County(PA-DELCO) SDC Demonstration

- 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 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
    - Establishing relationship
    - 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
    - Purchase amount placed on Allow Card
    - Monthly check-ins with Recovery Coach, or as determined by Participant
    - Recovery coach tracks expenditures

Asks and %'s By Category

General Tasks & Domains
23.27%

Self-Care
22.29%

Domestic Life
22.09%

Mobility
19.33%

Community, Social, & Civic Life
19.33%

Major Life Areas
14.593%

Snethen, G., Bilger, A., Maula, E., & Salzer, M.S. (in press). Exploring personal medicine as part of self-directed care: Expanding perspectives on medical necessity. Psychiatric Services.

Examples of Most Frequent Requests by Diagnosis

Example of most frequent requests by diagnosis		
Code	Example Request	Identified Major Life Goal
Schizophrenia Spectrum Disorder		
5701 Managing Diet & Fitness	Workout shoes	Improving my physical well being
8450 Acquiring a Job	Printer & Ink	I need a printer for and copier ink for my job search to copy resumes and work related identification.
4702 Utilizing Public Transportation	Transportation Pass	Tokens for bus rides to and from D&A groups 3x's a week. Need this to stay clean from drugs. Pay for transportation is a barrier.
4701 Utilizing a private motorized vehicle	Driving Lessons	Learn to drive. It will improve my life style to get a better job. I will be able to take my child to where ever I want to.
Bipolar Disorder		
4701 Utilizing a private motorized vehicle	Driving test fee	Go to driving school to learn how to drive and be more independent
2401 Handling Stress	Divorce Fee	Enhancing my relationship
5701 Managing Diet & Fitness	Gym Membership	To become more fit and healthy
2400 Handling Responsibilities	Paying Rent	Living responsibly, drug free, paying bills, and being happy
Major Depression		
4702 Utilizing Public Transportation	Monthly Transportation Pass	Becoming more independent
5702 Maintaining/Looking after one's health	Therapy Co-Pay	Maintain and control my mental health.
2401 Handling Stress	Pay Electric Bill	Reduce financial stress
2403 Handling depression	Household Furnishings	To feel like my home is a positive space

Snethen, G., Bilger, A., Maula, E., & Salzer, M.S. (in press). Exploring personal medicine as part of self-directed care: Expanding perspectives on medical necessity. Psychiatric Services.

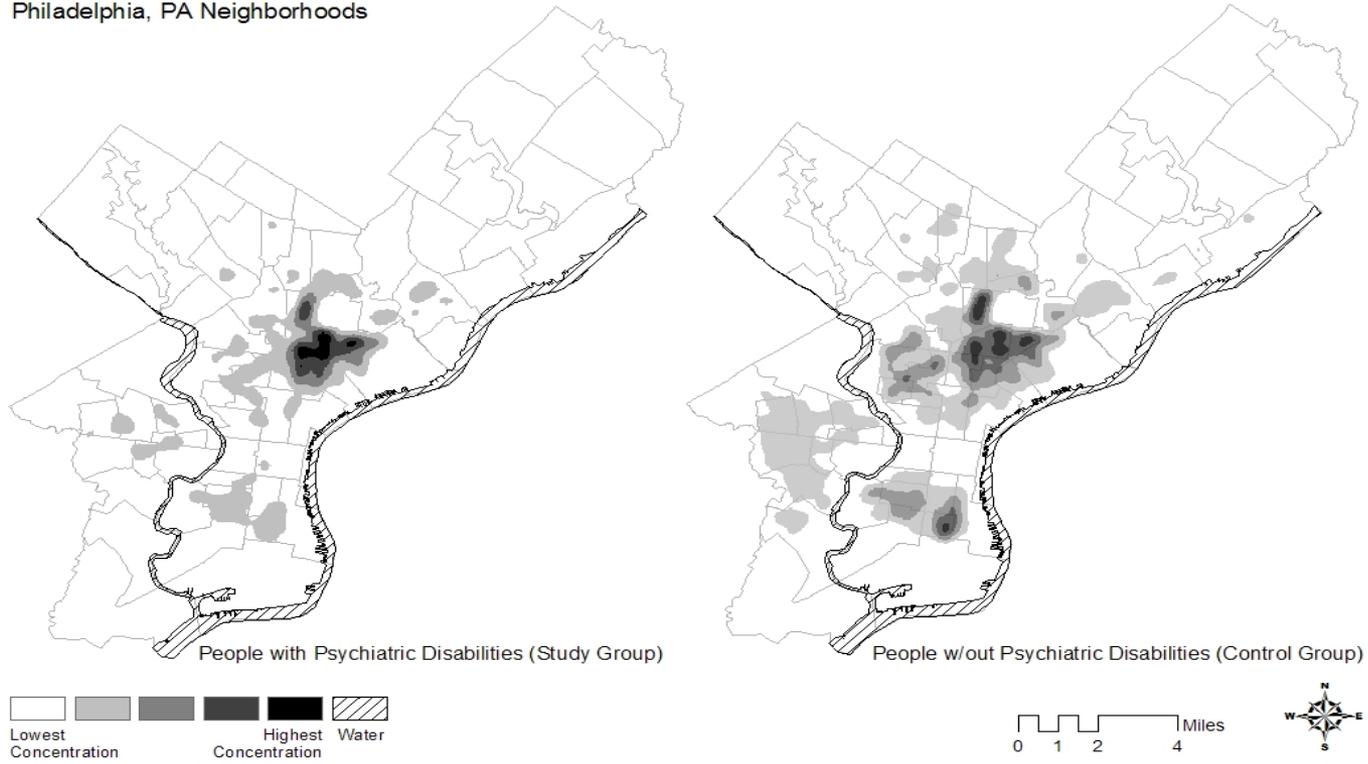# Fundamental #9: Identifying and Addressing Environmental Barriers

Common Barriers

- Prejudice and discrimination
- Poverty
  - Eldar Shafir (Princeton) – Research on the science of not having enough
  - "Povery impedes cognitive function" (Science, Aug 2013)
  - The strain of poverty drains cognitive resources, especially as tasks become more challenging and complex
- Transportation
- Rights
- Access to resources

Modest Residential Segregation


Residential Population Density, Ages 18 to 64
Philadelphia, PA Neighborhoods

People with Psychiatric Disabilities (Study Group)

People w/out Psychiatric Disabilities (Control Group)

Lowest Concentration — Highest Concentration — Water

0 1 2 4 Miles

Map Created By: J. Caplan and S. Metraux on January 18, 2005
Data Sources: US Census and Medicaid fee-for-service claims and eligibility records

From Metraux, Caplan, Klugman, Hadley (2007)

People Live Where Housing is Affordable

Median House Value
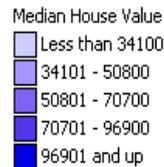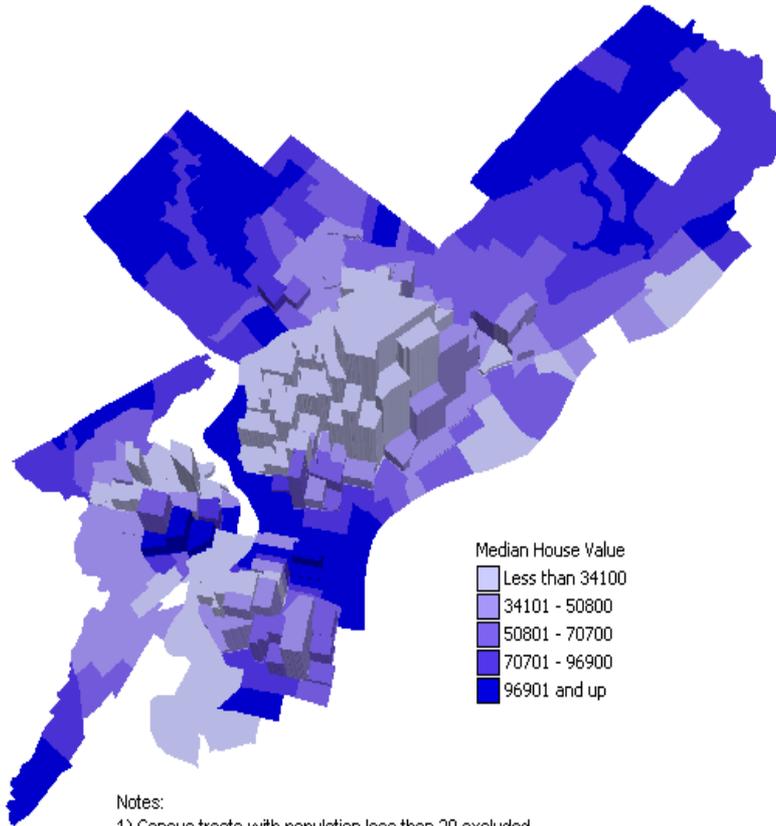
Median House Value
- Less than 34100
- 34101 - 50800
- 50801 - 70700
- 70701 - 96900
- 96901 and up
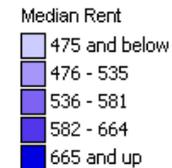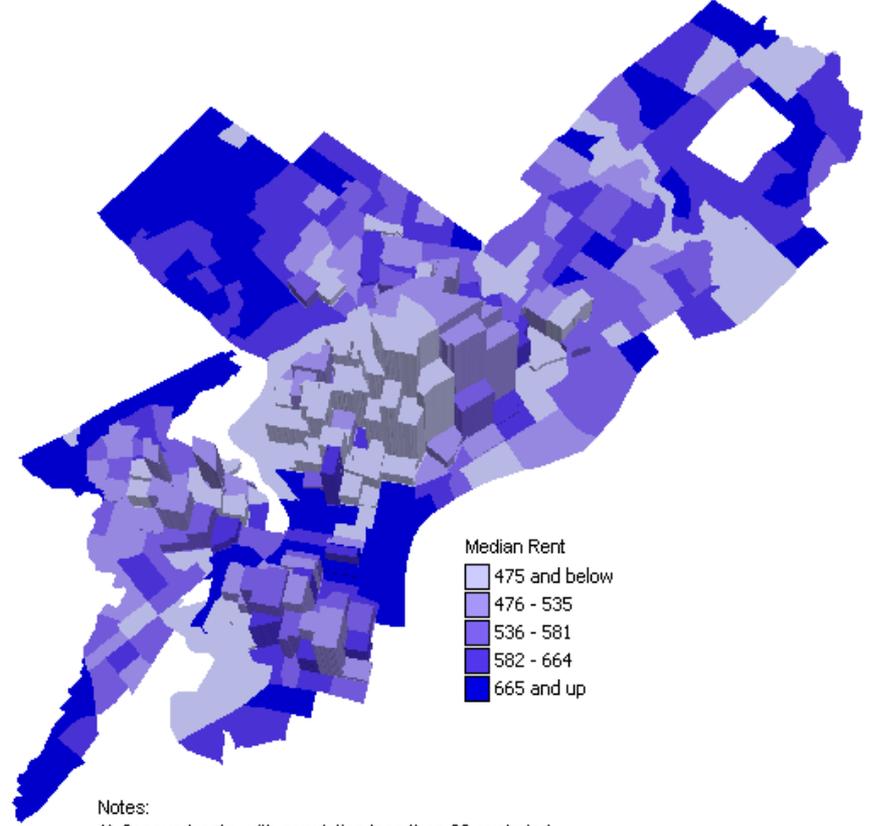
Notes:
1) Census tracts with population less than 20 excluded.
2) Higher elevation of a census tract represents higher density of mental health consumers receiving Medicaid in that tract.

Median Rent

Median Rent
- 475 and below
- 476 - 535
- 536 - 581
- 582 - 664
- 665 and up

Notes:
1) Census tracts with population less than 20 excluded.
2) Higher elevation of a census tract represents higher density of mental health consumers receiving Medicaid in that tract.

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Implications for Practice

- Develop the talking points and language for why community inclusion benefits everyone

- Create awareness of the strengths of individuals who have been seen only as having deficits

- Create respect for the uniqueness of all individuals…even those aspects that are viewed as "different" or deficits

- Create demand in the community for increased presence and participation

- Inclusion not just accommodation