

**Brandeis** THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Peer Support for People with Intellectual & Developmental Disabilities & Substance Use

Joanne Nicholson, PhD  
 Brandeis University  
 February 7, 2025



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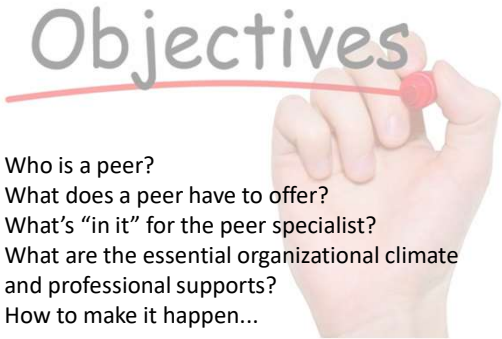
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# Objectives

- Who is a peer?
- What does a peer have to offer?
- What's "in it" for the peer specialist?
- What are the essential organizational climate and professional supports?
- How to make it happen...



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**Informed by projects supported by:**

- The National Institute on Disability, Independent Living & Rehabilitation
- The Patient-Centered Outcomes Research Institute
- The work of many, many team members, including Sharon Reif, Rachel Sayko Adams, Anne Valentine, Emily Ledingham, Allie Silverman, Ian Moura, and many other colleagues and community experts.

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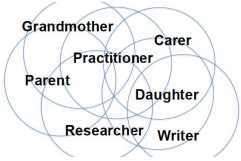
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**Who are we?** word cloud activity

Please write words or phrases that describe what you consider to be key aspects of your identity.

“No one you have been and no place you have gone ever leaves you.”  
Bruce Springsteen, *Born to Run* (2016)




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**What can we borrow?**

- Mental Health Peer Specialists...and people with IDD
- Recovery Coaches...and people with IDD
- Older Adult Services...and people with IDD
- Family Partners...
- Others...




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**Who is a peer? The notion of “fit”**

- Perceived similarity of characteristics? Shared identity?
- Too narrow a focus on any one aspect of “peeriness” may be unwarranted.
- Fit may change over time, as experiences & needs change.




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### What does a peer have to offer?

- Appreciates that recovery is not a linear path.
- Provides practical advice & feedback.
- Shares & demonstrate coping skills.
- Advocates & promotes access.
- Advises re: system navigation.
- Role models success.

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### What else does a peer have to offer?

- May be non-judgmental, non-stigmatizing, not oriented to psychopathology (e.g., strengths focus)
- Understands negative experiences.
- Offers hope & encouragement.
- Helps others feel less alone.

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### What's "in it" for the peer specialist?

- Benefits
  - Motivated by helping others
  - Sense of mastery, purpose
  - "Giving back"
- Challenges
  - Boundaries
  - Judicial use of self-disclosure
  - Potential for raising painful issues

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**Shifting to people with IDD & peer support...**

**For the person with IDD:** *"...The value in knowing someone who is like me, can be here with me, and offer me...living proof that recovery from what I'm going through is possible."*

**For the peer:** *"I've had this experience; let me help you through this...I know you're hurting, but it's gonna' be okay because I already did it and I came out of it...And once you feel better about it you want to share it."*

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**Question your assumptions. (Reif redux)**

- People with IDD do not need treatment.
- They are "non-compliant."
- Providers are reluctant to serve them.
- Individuals with IDD are complex.
- Autistic people have limited opportunity to use substances due to fewer social contacts.
- Substance use reduces social anxiety for Autistic people.
- Other characteristics marginalize people with IDD.

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**Consider your model of recovery.**  
Does recovery depend on cognitive, communication, & interpersonal/ social capabilities?

**Figure 1: Recovery Capital Framework**

<p><b>Social Capital</b> social group membership → provides resources, support, reciprocal obligations and benefits</p>	<p><b>Physical Capital</b> economic or financial assets → allows access to options for pursuing recovery</p>	<p>Identify individual strengths &amp; vulnerabilities. "One autistic person does not equal another autistic person does not equal another autistic person..."</p>
<p><b>Human Capital</b> knowledge, skills, education, health, traits → enables optimal negotiation of daily life</p>	<p><b>Cultural Capital</b> values, beliefs, from membership in cultural group → supports construct of systems of meaning to support recovery</p>	

The bottom line - How does the person you serve want to be supported?

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### Who is the right peer?

- A person may want someone “the same” or “different” from themselves.
- Ask the right questions.
- People’s needs may change.
- Choice is important.
- “The person with the disability is the expert in what they need.”



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### What does peer support typically look like?

- Office visit
- Coffee shop or McDonald’s
- Emergency room
- Treatment center
- Home visit
- Car ride
- In person
- Group



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### For people with IDD...

- Models relying on group interaction & sharing may not be a good fit.
- A feeling of lack of control or discomfort & accompanying anxiety may be more disabling.
- Choice is important; think “outside the box.”
- Online, asynchronous?
- Video game interactions?
- Email?
- Focus on preferences to tailor accommodations.



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For guests with disabilities, do you need any accessibility accommodations?

Yes

No, please select from the list below

- Bringing a Personal Assistant
- Need Bed moved to accommodate for mobility aid
- Prefer Wax Specialist to Wear Mask
- Preference to Have Wax Services Performed from Chair/Scooter
- Need Pictorial Direction (Guest is hearing impaired, non-verbal, etc.)
- Need Additional Time to Undress/Dress
- Chat Free Session Requested
- Cannot Lie Flat on back/ or face up
- Need Stool to Get into Bed

If you do not see an accommodation listed that meets your

A great example of asking about accommodations...

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### Cross-training peers or IDD peer models

- Training mental health peer specialists or recovery coaches to work with people with IDD
- Training people with IDD to work as peers.
- Training people with IDD in mental health & substance abuse treatment.
- Training must be accessible & disability-informed.

Academy Psychiatry  
https://doi.org/10.1007/s40596-024-02063-w

**IN BRIEF REPORT**

**Evaluation of an Interprofessional Educational Intervention in Mental Health and Intellectual and Developmental Disability for Health and Social Service Trainees**

Gabriel Tarzi<sup>1</sup>, Anupam Thakur<sup>1,2</sup>, Nicole Bobbette<sup>3</sup>, Megan Pflatzke<sup>4</sup>, Gill Lefkowitz<sup>5</sup>, Kendra Thomson<sup>6\*</sup>, Alicia Thatchee<sup>7</sup>, Syeda Hasan<sup>1,2</sup>, Aileen Foglia<sup>8</sup>, Marissa Blake<sup>9</sup>, Anna Hines<sup>9</sup>, Yona Lunsky<sup>9</sup>

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### Community Autism Peer Specialist (CAPS) Program – Philadelphia, PA



- Based on the Certified Peer Specialist model in mental health
- CAPS pairs an individual with autism who has completed a peer support training program, with other individuals with autism to achieve personal wellness & community integration goals
- Goals may include: employment, education, independent living, self-care, relationships, transportation, community engagement

C.B.H. DBHIDS MENTAL HEALTH PARTNER ORGANIZATIONS PAC

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### CAPS Program Development

**CAPS Curriculum:** Val Paradiz, a self-advocate and mom of a son with autism developed a CAPS curriculum for young adults and adults with Autism (160 lessons/modules).



**CAPS Training Program:**

43 individuals with Autism graduated from the CAPS training class. They completed a 75-hour training consisting of classroom instruction, self-paced homework, & four hours shadowing a mobile mental health peer specialist in the field.



**CAPS Advisory Board:** Self-advocates, care-givers, & professionals reviewed & provided feedback on the curriculum, training program & implementation plan.



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### The benefits of CAPS

- “Autistic peers have fewer stigmatizing beliefs & attitudes towards autism.”
- “Autistic people can develop close bonds, demonstrate empathy, and have less stressful communication with autistic people than with non-autistic people.”
- “They are more likely to focus on strengths.”
- “First positive employment experience ever.”



Journal of Autism and Developmental Disorders  
<https://doi.org/10.1007/s10803-022-05816-4>

ORIGINAL PAPER

#### Autistic-Delivered Peer Support: A Feasibility Study

Lindsay L. Shea<sup>1</sup> · Mi-Yeet Wong<sup>1</sup> · Wei Song<sup>2</sup> · Katy Kaplan<sup>3</sup> · Disha Uppal<sup>1</sup> · Mark S. Salzer<sup>2</sup>

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### Considerations for parents with IDD & peers

- Stigma & assumptions
- Values re: families, parenting, & children
- Lack of services, resources & social support
- “Fit” – children of different ages & stages



International Journal of Environmental Research and Public Health



Article  
Mothers with Intellectual/Developmental Disabilities and Behavioral Health Conditions and Community Experts Provide Recommendations for Treatment/Services, Systems, and Research

Jeanne Nicholson<sup>1,†</sup>, Shayna Mazel<sup>2,†</sup>, Kelechi Fughuan<sup>3</sup> and Allie Silverman<sup>4</sup>

(2023), International Journal of Environmental Research and Public Health, 20, 5876. <https://doi.org/10.3390/ijerph20105876>.

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**Peer training recommendations from our advisors:**

- Question your assumptions.
- Recognize ways in which lived experiences can inform your work.
- Be respectful of, sensitive to, & make practical adaptations for physical, cognitive, & sensory needs & challenges.
- Consider how to inquire about needs that may not be readily observable.
- Remember that any disability involves trauma.
- Manage your own wellness.



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**Enhancing organizational context and capacity:**

- Provide a well-specified job description
- Train, coach & support
- Identify multiple champions & supporters
- Strategize to get organizational & staff “buy in”
- Integrate peers into team & staff
- Develop relevant policies & procedures
- Consider funding & sustainability



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**How to make it happen?**

- Engage people with IDD.
- Assess needs & experiences.
- Identify barriers & facilitators.
- Network & nurture the support of champions.
- Consider acceptability, accessibility, & feasibility to lay the groundwork for scalability & sustainability.



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**Contact:**  
jnicholson@brandeis.edu



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