Promoting Direct Support Professional Resilience: Synthesizing Findings to Make an Impact

Melissa L. Desroches, PhD, RN, CNE

Assistant Professor, Community Nursing

University of Massachusetts Dartmouth

Session Outcomes

1. Describe at least 3 practices DSPs can use to help them thrive in their roles.

2. Identify at least 2 strategies others can use to support DSPs to be resilient.

Importance of Direct Support Professionals

- Prior to the pandemic, ~1.3 million DSPs provided support to people with IDD in the USA   (Institute on Community Integration, 2022)

- A direct support professional (DSPs) is someone who works directly with people with IDD to help them meet their daily needs
  - Support adults with IDD to live in community settings
  - Helps people to be engaged community members
  - Different skill set from 'caregiving'

DSPs are a Stigmatized Workforce

- Most DSPs are from historically disadvantaged backgrounds
  - Female
  - Of color
  - Middle-aged or older
  - Reliant on some form of public assistance   (PHI, 2020)

- DSPs face stigma by association with people with IDD. (National Direct Service Workforce Resource Center, 2008)

- An "invisible" workforce with little to no support (Kirschner et al., 2020)

The Massive DSP Workforce Shortage

Pre-pandemic: "America's Direct Support Workforce Crisis"

- President's Council on Intellectual Disabilities Report to the President (2017) revealing untenable staffing levels due to increased stress and burnout

- 8 contributing factors identified:

  - High staff turnover
  - Aging population
  - Increased survival of people with complex conditions
  - Fewer people entering DSP workforce

  - Low wages, benefits & little time off
  - High stress & job demands, "on" 24/7
  - Insufficient training
  - Lack of recognition and status for skilled DSPs

… then COVID-19…

On top of a "baseline" workforce crisis with a 44% annual turnover rate
(National Core Indicators, 2020)

'We're beginning to see the collapse of
the system': Agencies that serve people
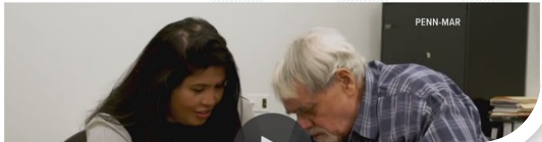with disabilities call for more funds to pay
staff

By Kate Giammarise, WESA · October 7, 2021

NEWS

A workforce in crisis: Disability
services are seeing a shortage of
direct support staff

—

Direct support professionals are a lifeline to people with disabilities, but
the turnover rate has reached a crisis level.

PENN-MAR

The shortage of care
workers' big impact on
people with
developmental disabilities

By Monica Sandreczki / North Country Public Radio
Published February 8, 2022 at 2:14 PM EST

Monica Sandreczki / North Country Public Radio

Yet, some DSPs stayed, and are thriving

- Desroches et al's (2020) study of IDD nurses' perspectives of challenges related to the pandemic revealed that many DSPs were flexible, creative, and held positive attitudes, "going above and beyond", despite immense challenges.

Image: https://www.dol.gov/agencies/odep/program-areas/individuals/DSP

Shifting Focus to DSP Resilience

- Much attention has been paid to DSP stress and burnout, yet little research has explored what helps DSPs to persevere through challenges and remain in their roles

- Resilience = the ability to thrive in the face of challenges and adversity

Review of Literature on DSP Resilience

*3 studies addressed DSP resilience in midwestern USA:*

- Resilience mediates the relationship between self-care and professional quality of life (Keesler & Troxel, 2020)

- DSPs with high resilience indicators were motivated by family, social relationships, and desire to better society (Crane & Havercamp, 2020)

- Resilience is negatively associated with emotional exhaustion (Nevill & Havercamp, 2019)

Interventions for DSP Resilience

- 2-day mindfulness and emotional coping training in the UK significantly reduced DSP's *psychological distress* (Noone & Hastings, 2009)

- Brief, inservice resilience workshop for DSPs of people with IDD and challenging behavior resulted in decreased *negative emotional reactions* (Ingham & colleagues, 2013)

- Neither intervention was guided by resilience theory nor measured resilience

A Major Gap in the Literature

No studies have examined DSP resilience from the perspective and in the voice of the DSP
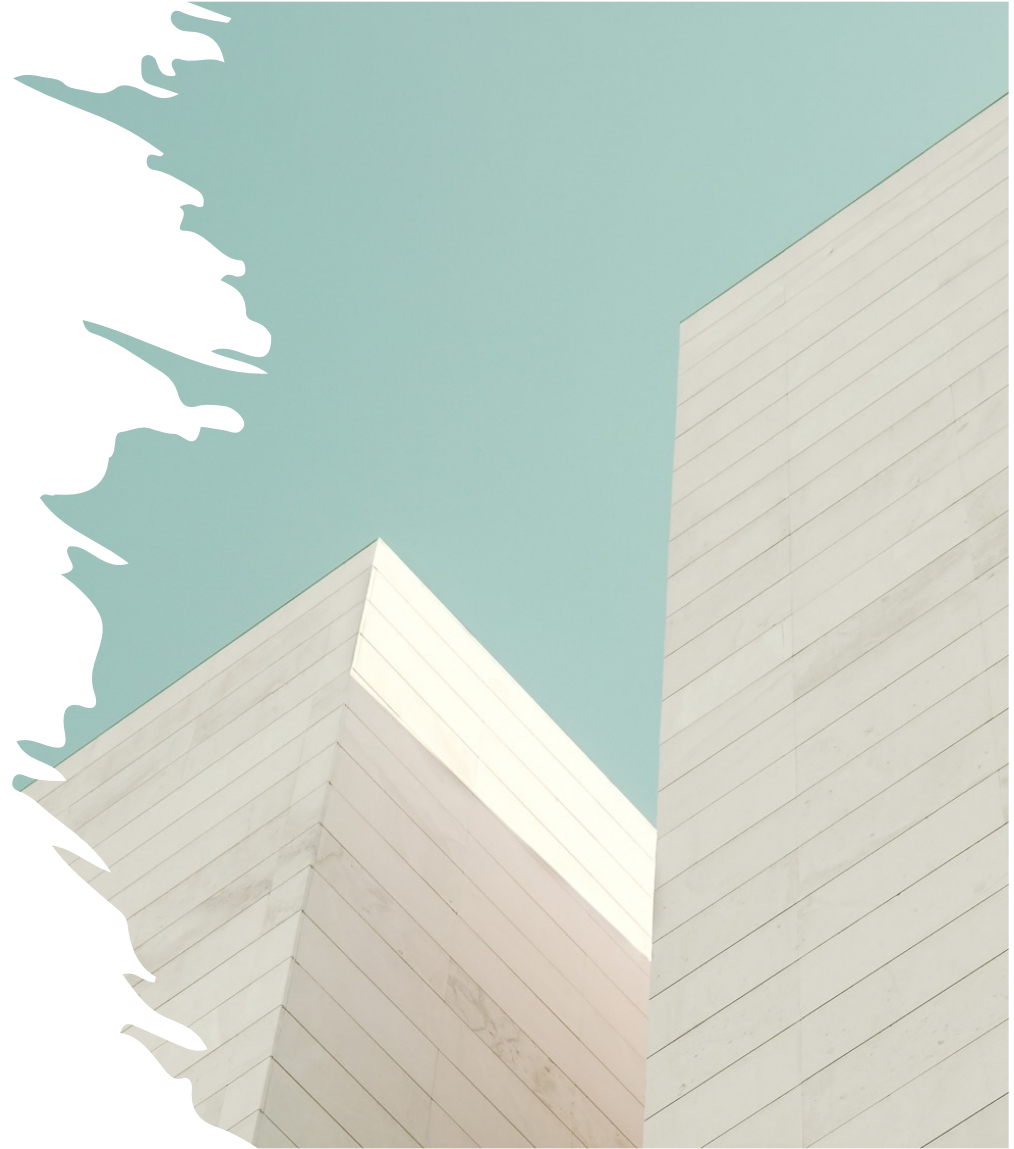
COVID-19 as a Case Study in DSP Resilience

The DSP Thrive! Research Study

Purpose: To identify practices that contribute to the resilience of DSPs of adults with IDD

Design: Qualitative descriptive design using Zoom videoconferencing interviews, February to August 2021

Sample: 10 DSPs who were identified by their employers or self-identified as being highly resilient

Recruitment: Email flyer invitations sent to developmental disability provider agencies

The DSPs who Responded

- 90% female (1 male)
- 80% white (1 African American, 1 Cape Verdean)
- 50% worked in group homes (other = job coach, day habilitation)
- 70% from Northeast (3 from Midwest)
- Age range 20-51 (several non-disclosed)
- Years of experience as DSP 1-16 years

Findings

- Making a meaningful connection with people who do not use verbal language

- Understanding the bigger picture of what is going on with the person

- Venting with a trusted colleague to cope with stress

- A foundational aspect of teamwork-
  - with other DSPs for safe and effective care
  - with people with IDD in group settings

COMMUNICATION

With people with IDD, families, other DSPs and staff

" You need to listen, you really need to listen, I listened to the clients, you have to listen to them...I sit back even in our conversations and when they're having conversations amongst each other, I listened to them and that's how I learned and that just different things they say to each other and what their likes and dislikes and I'm like "Hmm"... and I learn" (Participant D).
"

SELF WORTH & RECOGNITION

Positive recognition from people with IDD, family members, and agency leadership

"You know, don't look at it just as a paycheck. I mean granted, yes, it pays my bills, but at the same time, I feel that it's more meaningful than that. Way more meaningful than that" (Participant A).

- Low societal value placed on DSPs contributes to low self-esteem

- Having voice heard by agency leaders, with follow-up

- Positive feedback from people with IDD and families

- Self-worth from helping others and positive impact on the lives of people with IDD

- Getting to know the person with IDD as an individual from experience

- Equity, respect, shared humanness overcome IDD label

- Discernment in sharing DSPs "real life"

- No sugarcoating with people with IDD

- Opportunity for people with IDD to make choices and try

AUTHENTIC EQUITABLE RELATIONSHIPS

with People with IDD

"They're people, just like we are. You know, they may have a disability, but they're just like we are" (Participant D).

EMBRACE CHANGE & LEARNING

"And the sooner you learn that the more flexible you are, and you can just roll with it, because every day something new and different is happening... that's just the nature of the job, you've got to roll with it" (Participant G).

- Unpredictable role = flexibility & adaptability

- Recognition that change is inevitable

- Letting go of control of having things done a certain way

- Putting a positive spin on changes

- Reflecting on what could be learned from past experiences

- Opportunities for education and training and asking questions

- Applying policies and procedures and tailoring approach to person with IDD

- Respecting the boundaries of people with IDD and their families in terms of communication and values and beliefs

- Setting boundaries around participants with IDD calling/texting during non-work hours

- Process of learning own limits in terms of working additional shifts and with people with challenging behaviors

- Recognizing symptoms of burnout and adapting boundaries

BOUNDARIES

with People and Time

"What's very important... is that there are boundaries... we can still get along and we can be happy and enjoy each other, you know, but there's just so much you can do. Those boundaries are very important" (Participant N).

INTENTIONAL MINDSET

"I just come in with my 'hey, we're gonna have a good day, this is what's going to be, guys, and you know, let's get to it" (Participant A).

- Conscious decision to not bring problems from their personal lives into work

- Empathy vs sympathy- viewing situations from the perspective of the person with IDD

- Calmness, as opposed to emotional reactivity, in response to challenging situations

- Recognition that DSP mindset influences the tone of the day for the person with IDD

- Cultivating a positive atmosphere

- Natural outflow of spending time with people with IDD

- A daily practice- purposively cultivated and incorporated into daily activities

- Helped to motivate people with IDD to meet goals in the absence of pay

- Use of humor with self and people with IDD to cope with challenging situations

- Involved telling jokes, celebrating holidays and events, asking for fun ideas from people with IDD, playful teasing, etc

HUMOR & FUN

"And I have to try to make everything fun, because if it's not fun, they don't get, most of them don't get paid, so there's no real incentive to do what I'm encouraging them to do, unless it's something that's fun. Even if it's not fun we have to encourage "We will have fun after" (Participant E).

SELF-CARE

If you can't take care of yourself, you can't take care of nobody else, and guys, also I live by that rule... You represent like who you are, as a person, and self-care is important" (Participant A).

- Time for what matters most to the DSP

- Strategies varied by individual: spending time with pets & loved ones, exercise, hydration, reading, meditation, personal grooming, going on a coffee run

- Some self-care shared with people with IDD during the workday, ie. exercise, hydration, meditation

- Mindful moments in nature

- Speaking with friends and loved ones to destress

- Direct reference to faith, prayer, and spirituality by some DSPs

- Self-reflection as an opportunity to learn and grow in light of a larger reason for being

- "At the end of the day" approach to interpreting daily challenges, as opposed to reacting in the moment

- Idea of being a DSP as "meant to be"

- Challenges caused DSPs to have greater appreciation for time and what is truly important in life

SPIRITUALITY & BIGGER PICTURE

"I did turn more into spirituality. Not just like questioning life, reading or science articles, but also really paying attention... Just really paying attention...[to] what's happening so that actually was an unexpected stress relief" (Participant G).

Discussion

- Overlap with factors that contribute to nurse resilience: focus on a positive mindset, embracing learning and self-care, paying attention to the present moment, facilitating social connections (Wei et al., 2019)

- Overlap with resilience in people with IDD: supportive social network, daily leisure activities, accepting life changes with a positive attitude (Scheffers et al., 2020)

- DSP = letting go of control, Person with IDD = increased sense of control (Scheffers et al., 2020)

Study Strengths & Limitations

- First study to investigate DSP resilience from the perspective of resilient DSPs

- Sample predominantly White and from the Northeast US

- All DSPs employed 1+ years; may not remember what helped them to become resilient in the first year of employment

- Does not account for change in resilience over time

What Can DSPs Do?

- Select one of the 9 resilience practices that speaks to you and set a goal to incorporate it into your daily routine for 3 weeks

- Use the 4 laws of behavior change (Clear, 2018)

MAKE IT OBVIOUS

MAKE IT REWARDING

MAKE IT EASY

MAKE IT SATISFYING

What can DSP employers do?

- Encourage resilience activities within the workplace culture
- Recognize DSP strengths and accomplishments, formally and informally
- Ensure DSPs have adequate training related to communication and for their specific job tasks and have the opportunity to ask questions; peer mentoring possibility
- Ask for DSPs perspectives and follow-up individually
- Support DSPs to infuse humor and fun into daily practice and activities– this is not for the purpose of fun but to support wellbeing of people with IDD and the DSPs who support them!

How can we advocate for DSPs?

- Resilience helps people to thrive through challenging circumstances
- We can act to change the challenging circumstances through policy action
  - Low DSP pay
  - Lack of recognition as a federally-designated workforce
- Advocate by who you vote for, contact your legislators, and join advocacy organizations, like the state Arc chapters, to guide your advocacy

Be Part of the Change

Not doing anything *is* doing something!

-- Bill Maher

Thank you!

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