National Leadership Consortium Bulletin

The Intersection of Mental Health and IDD Leadership

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About the Bulletin

The National Leadership Consortium Bulletin is a free, web-based publication dedicated to providing relevant, trustworthy, and thought-provoking information to leaders, practitioners, and people with disabilities and their families involved in the field of developmental disabilities support services. The Bulletin will serve as a bridge between scientific journals and day-to-day leadership, exploring timely research and policy issues in the leadership and disabilities fields with the aim of promoting organizational change and assisting leaders to support people with disabilities to experience inclusive, valuable, and meaningful lives.

About the National Leadership Consortium

Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.

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Introduction: The Intersection of Mental Health and IDD Leadership

About one in five adults live with diagnosable mental illness. People with IDD have higher incidences of mental health conditions and behavioral support needs than people without IDD but research shows they may not receive needed care from community providers. In this Issue, we will explore this topic, including the gap between support needs and availability and access, successes and challenges across the system related to these dual needs, mental health support for direct support workers and family members, and highlights of impactful leaders and leadership related to mental health supports across the IDD sector.

In Mental Health and IDD Service Leadership, Amanda Rich explores the intersection of mental health and IDD services by showcasing data, the impact of challenges, strategies for success, and what effective leadership can look like in this overlap. In Bridging the Mental Health Divide for Individuals with Intellectual Disabilities, Jeanne Farr, NADD Executive Director, highlights critical research and publications related to IDD and mental health featured in the Journal of Mental Health Research in Intellectual Disabilities. From an interview with Victor Pereira, a leader in advocacy in the intersection of disability and mental health, we learn about the kinds of resources available and how leaders are and can be involved in this work.

A consistent advocate for mental health supports and improving systems of support within and outside of the IDD sector, Humanizing Human Service Systems: A Small Piece of Dave Hingsburger's Long Legacy highlights the amazing work done by Dave Hingsburger throughout his life. One area in the system that is often lacking is grief support. Grieving is a large part of mental health but in the article, Grief Happens: Supporting People Through Loss, Amanda Gee shares why our systems of support often do not support people in this way well and what can be done to improve. In the article, Improving Services for People with Co-Occurring IDD and Mental and/or Behavioral Health Support Needs: Lessons Learned from Research in Washington State, Cory Gilden highlights research the National Leadership Consortium did in Washington around some successes and challenges in supporting people with IDD and mental and behavioral support needs and some major barriers to doing so effectively.

Although many articles focus on those with IDD, we also know there is a significant impact on caregiver mental health. In Caregiver Mental Health: A Review of Research Findings, readers can learn about study findings related to caregiver mental health and why this is an important topic to address. In an interview with Brittany Ellis, an IDD peer Support Specialist, she shares some of the impactful ways that peer mentorship can help support positive mental health. Lastly, representatives from a managed care entity in Michigan share how mental health care is key to whole person health and how they are creating better systems of whole person support by collaborating with organizations, providers, and people with IDD to provide better services.

We hope you enjoy reading this Issue,

Kristen Loomis Greenidge

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Mental Health and IDD Service Leadership

By Amanda Rich

- Mental health is needed for wellbeing.
- Mental health exists on a spectrum.
- Mental health challenges and mental illness are common and can negatively impact individuals and organizations.
- People with intellectual and developmental disabilities are at a greater risk of experiencing challenges to their mental health and face barriers in getting mental health support.
- Leaders should recognize that mental health is important to them, their staff, the people they support, and the organization.

How Are You, Really?

Are you feeling stressed, anxious, a little depressed lately? If so, there's a good chance you are in the wonderful company of many of your neighbors, coworkers, and people with disabilities your organization supports. In the United States and around the world about one in five adults live with diagnosable mental illness. Additionally, even more of us experience mental health challenges that may not rise to the level of a diagnosable illness but still impact our wellbeing. Studies have found that rates of stress have increased amongst every age group in the years following the pandemic. Those who work in human services fields often face even higher levels of chronic stress, emotional exhaustion, and adversity than the general population. People with intellectual and developmental disabilities and their families also face higher rates of mental and behavioral health challenges than the general population. Is this a problem? Not necessarily. Mental health exists on a continuum, and everyone will experience hard times at some point in their lives. However, when the distress of people providing and using services is chronic, severe, unacknowledged, not understood, and/or unmanaged, it can have negative impact on individual's health and wellbeing and on the health, wellbeing and effectiveness of the organization itself.

What Is Mental Health?

The World Health Organization defines mental health as "a state of mental well-being that enables people to cope with the stress of life, realize their abilities, learn well and work well, and contribute to their community." They note that mental health is not the absence of a mental health disorder but something that exists on a continuum and is experienced differently by different people. People with mental illness, when well-supported, can experience stronger mental health and people without diagnosable mental disorders may also have times in which they face significant challenges to their mental health.

Mental Illness & Mental Health Disorders

Mental illness or mental health disorders refer to a wide range of experiences that impact how you feel, think, and act in a way that significantly effects your ability to function in major areas of life. There are many possible symptoms of mental health disorders that can exist with varying severity or intensity. They can include changes in eating and sleeping patterns, problematic use of drugs, alcohol, gambling or sex, difficulty coping with daily challenges, detachment from reality, withdrawal from friends, families and activities that have previously brought joy, excessive worry, feelings of guilt, intrusive thoughts, mood swings, constant feelings of sadness, self-injury, and suicidal thinking or behavior.

Mental Health Disorders in People with IDD and Support Providers

People with intellectual and developmental disabilities have a higher rate of co-occurring mental disorders than the general population, but until recently clinicians have been reluctant to provide mental health diagnoses. Until recently, psychological pain that was demonstrated through destructive, disruptive, self-injurious, or aggressive behavior was instead attributed to the person's intellectual or developmental disability as opposed to emotional or psychological distress. This is sometimes called diagnostic overshowing and continues to be a challenge for people with IDD in accessing effective psychological support. People with IDD who do not use standard spoken or sign language, including those who had higher behavioral support needs are less likely to be diagnosed with a mental health condition.

Even when people with IDD have a diagnosis of a mental health disorder, many face additional challenges to accessing mental health support. One reason is a lack of community-based mental health workers in general and fewer who are willing to work with people with IDD. Many community-based mental health providers feel ill-prepared to serve people with intellectual and developmental disabilities. Additionally, leaders of disability support organizations have reported difficulty in helping the people they serve to find and pay for mental health care.

Direct support providers and people with intellectual and developmental disabilities also face higher rates of exposure to adverse and potentially traumatic experiences which increases their risk for mental health challenges. When people who have experienced significant adversity and have limited financial resources, natural social support networks, and limited access to mental health care, their risk of experiencing Post Traumatic Stress Disorder or other stress-related mental health conditions increases.

There is an old saying that goes, "Pain that is not transformed is transferred" (attributed to Rohor, 2016). Some researchers propose that through parallel processes, human systems like disability service organizations can mirror the distress of the people within them. These are sometimes referred to as "traumatized organizations." Traumatized organizations have organizational cultures, policies, and practices that focus on immediate survival over achieving the long-term mission. They lose their ability to provide a safe environment for their clients and staff and trigger mistrust. Some signs of a traumatized organization include high turnover, high rates of staff burnout, worker error, and abuse. Traumatized organizations can cause those within them even more distress.

What Does It Mean for Me?

- Remember that you matter. Often, we become so focused on the needs of our families, friends, our staff, and the people that we serve that we forget that we have needs too. That doesn't mean our needs go away. Neglecting our own needs for too long can increase our risk for psychological distress.
- Practice self-compassion. Self-compassion or self-kindness is a skill that can be developed. It involves at least three things — mindfulness or noticing what is present without judgment; remembering that suffering and pain are universal human experiences that connect us with others; and taking steps (even small ones) to ease that pain when possible. Self-compassion supports mental health.
- Develop a self-care plan. Self-care plans don't simply involve writing "bubble bath" on your weekly calendar. They involve critical reflections on what you need holistically in your life and steps you can realistically take to meet a variety of those needs including social, financial, spiritual, emotional, and physical needs, on a regular basis.
- If stress, distress, or other mental health challenges are impacting major areas of your life consider reaching out for help. Websites like Psychology Today can help to find mental health support in your area.

What Does It Mean for My Organization?

- Support those you lead in developing an awareness and language around emotions, mental health, and mental health challenges. Having names for difficult experiences often makes them feel less isolating and can provide a clearer path to navigate them. Mental health challenges like burnout and compassion fatigue are common workplace hazards in helping professions and education can help people recognize symptoms and intervene early.
- Learn and consider taking steps to adopt trauma-informed care into your organization's policies and practices. Trauma-informed care involves the integration of knowledge of psychological trauma, distress, and healing into an organization's policies and practices. It is based off the belief that all people within human services organizations may have experienced trauma or adversity and can benefit from contexts of relational, physical, and psychological safety and support. There are many tools for helping your organization become more trauma informed. Karen Treisman's book *A Treasure Box for Creating Trauma-Informed Organizations* and The Trauma-Informed Care Implementation Resource Center are great places to start. Issue 1 of the Bulletin also covers topics related to Trauma Informed Care.
- Consider how your organization identifies those within your organization facing psychological distress and the resources you currently have (or need) to support them. Make sure information about Employee Assistance Programs, if your organization has one, is easily accessible.

What Does It Mean for the Field?

- Listen and respond to people with the lived experience of intellectual and developmental disabilities and mental health disorders from diverse backgrounds. Their expertise will help to identify and navigate barriers to better mental health support.
- Leaders must continue to ensure that those who work in the field and the broader community recognize that people with IDD, including those who don't use traditional methods of communication, have complex inner worlds like everyone else and are deserving of effective treatment and compassion when in distress. Ableism is a source of psychological (and physical) harm for people with intellectual and developmental disabilities. It is common in the broader community and within disability service organizations.
- Changes in behavior are often the best indicators of distress for people who do not use standard means of communication. Help staff learn to notice, listen to, and work to understand behavior and make sure there are protocols in place to ensure physical ailments are ruled out as a potential cause.
- Foster cross-sector collaboration that leads to expertise sharing and improved service coordination across the mental health and intellectual and developmental disability sectors. This may involve advocating for a greater inclusivity of the experience of IDD in mental health provider training programs and vice versa.
- Provide better support for frontline workers. Supporting workers' mental wellbeing involves at least in part providing greater financial stability and access to health care.

If you or someone you know is experiencing major distress and/or suicidal thoughts, help is available. Call 1-800-273-8255 or text 988.

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Bridging the Mental Health Divide for Individuals with Intellectual Disabilities

By Jeanne Farr

- The articles in the Journal of Mental Health Research in Intellectual Disabilities explore many important issues related to people with IDD and mental health.
- Recent articles in the journal highlight issues for people with IDD like not enough individualized mental health services or crisis support.
- More collaboration between researchers, healthcare providers, and policymakers can help work toward solutions for better mental health services for people with IDD.

Mental health is a critical but often overlooked aspect of life for individuals with intellectual and developmental disabilities. Research consistently shows that they experience higher rates of anxiety, depression, and other mental health conditions than the general population, yet they often face barriers to care, stigma, and a lack of specialized services. Despite the growing awareness of these issues, many individuals still struggle to receive appropriate care. For those with intellectual disabilities, social isolation, discrimination, and lack of access to mental health services further exacerbate these challenges.

The Journal of Mental Health Research in Intellectual Disabilities (JMHRID) has been publishing important studies on these issues since 2008. As Dr. Angela Hassiotis, the journal's editor-in-chief from 2016 to 2025, points out, the need for specialized mental health research remains urgent. Despite increasing awareness, mental health services for individuals with intellectual disabilities remain inconsistent and underfunded, especially in comparison to other conditions.

This article highlights recent research trends and key findings from the past two years, emphasizing:

- The growing recognition of mental health needs in this population.
- The importance of tailored interventions and improved service models.
- The role of crisis intervention strategies in reducing psychiatric hospitalizations.
- The under-researched issue of suicidality among individuals with intellectual disabilities.

The following are three research trends in the journal and their results in terms of implications for our field.

➊ The Need for Mental Health Services for Autistic Individuals with Intellectual Disabilities.

One of the most pressing concerns in the field is the lack of tailored mental health services for Autistic individuals with intellectual disabilities. A recent study by Hellerud et al. examined the mental health services available for Autistic individuals with intellectual disabilities. Researchers found that many people in this group receive general psychiatric care rather than tailored interventions. Key findings include:

- A high reliance on psychotropic medications but a lack of specialized mental health treatments.
- Limited access to trained professionals who understand the unique challenges of this population.
- Inconsistent use of best practices in psychiatric care.

Implication for our field: The study emphasizes the need for specialized mental health services that focus on the unique needs of Autistic individuals with intellectual disabilities. Expanding professional training and improving coordination among healthcare providers can lead to better outcomes.

❷ Importance of Crisis Intervention Strategies to Reduce Hospitalizations

While access to specialized mental health care is essential, another critical issue is how to support individuals with IDD during moments of crisis. Without proper intervention, many face unnecessary psychiatric hospitalizations, which can be disruptive and distressing. A systematic review by Tai et al., highlights the effectiveness of crisis intervention programs in addressing this challenge. Their findings show that:

- Rapid-response crisis teams can help stabilize individuals in the community, reducing hospital admissions.
- Specialized crisis care models, such as inpatient alternatives, improve outcomes.
- Service gaps remain, including inconsistent care and limited crisis support in many areas.

Implication for our field: Expanding mobile crisis teams and specialized community-based support can prevent psychiatric admissions and provide more appropriate care. Better coordination between mental health services and intellectual disability support systems is needed.

❸ Need to Recognize and Address Suicide Risk in Individuals with Intellectual Disabilities

One of the most alarming gaps in research and care is the issue of suicidality among individuals with IDD. For too long, assumptions that this population is not at risk have led to under-recognition and a lack of appropriate support. However, recent research by Chan and Bhandarkar reveals the urgent need to address this overlooked crisis. Their systematic review of existing literature found that:

- Many assume individuals with intellectual disabilities are not at risk of suicide, leading to under-diagnosis.
- Risk factors include co-occurring mental health conditions, social isolation, and lack of support.
- There are few assessment tools designed specifically for this population, making it harder to identify individuals at risk.

Implication for our field: There is an urgent need for better suicide risk assessment tools, increased awareness among clinicians, and tailored prevention strategies. More research is also needed to develop effective interventions.

The latest research in JMHRID underscores the urgent need for improved mental health services, crisis intervention, and suicide prevention strategies for individuals with intellectual disabilities. To address these challenges, we need:

- Stronger collaboration between researchers, healthcare providers, and policymakers.
- Expanded crisis response and intervention services to reduce hospitalizations.
- More specialized mental health care tailored to the needs of individuals with intellectual disabilities.
- Increased research and awareness to tackle under-recognized issues like suicidality.

Addressing these gaps requires collaboration between mental health professionals, educators, and community organizations to ensure that individuals with intellectual disabilities receive equitable, specialized, and effective mental health support.

By making mental health a priority for individuals with intellectual disabilities, we can reduce stigma, improve access to care, and enhance quality of life for this often-overlooked population.

NADD

Jeanne Farr *is the CEO of NADD, an Association for People with Intellectual/Developmental Disabilities and Co-Occurring Mental Health Conditions. She has an M.A. in Intercultural Relations from the School of International Studies at the University of the Pacific and has completed executive leadership programs at Harvard Business School, Columbia Business School, and the Kellogg School of Business. Jeanne is passionate about improving access to quality mental health care for people with IDD. Contact Jeanne at jfarr@thenadd.org.*

Leadership Perspectives: How Victor Pereira and the Centre for Addiction and Mental Health are Supporting People at the Intersection of Disability and Mental Health

Interview with Victor Pereira, Conducted by Caitlin Bailey

Our team met with Victor Pereira to talk about his experience and work at the intersection of disability and mental health. As a person who has been doing this work for his entire career, Victor shared his knowledge about what is needed to make sure that people get the support they need, overcome stigma around mental health and disability, and how to lead in organizations that promote mental health and wellbeing.

- People with disabilities often struggle to get the mental health support they need.
- In Canada, the Centre for Addiction and Mental Health creates resources, like a podcast and easy read documents, to help people with disabilities get resources related to mental health.
- Professionals, advocates, and people involved in the disability field need to talk more about disability and mental health and make services better for people.
- To lead organizations that promote mental health and wellbeing, leaders need to be passionate and leave their egos behind.

Caitlin Victor, thank you so much for meeting with me. Can you tell us how you got into this work at the intersection of disability and mental health?

Victor It all started with the school system and how we were treated unfairly, poorly. I was always a hyperactive kid and always wanted to make people smile. That's all I wanted to do, and so that's what irritated teachers the most. I was constantly sent to the principal's office for acting out or making jokes. It's just my nature to help people feel good.

The reason I got into this work really is so that I can speak positively about people's special needs and how we deserve more representation and speak about how we're discriminated against by the government, by the teachers, by even our own caregivers, even by family at some point. I know some people who don't have services that I do and they're doing well, and I know some people who have more services than I do, and they're not doing well — there's something missing.

I'm not here to speak on behalf of everybody, but if I can change one person's life by saying, 'Hey, you may be hyperactive, but that is because you're passionate.'

I'm passionate about people with special needs. I've seen firsthand how discriminated against they are. First, I went with my wonderful sister to speak at universities here and there, no big deal. It was at a place called Drama Way because they noticed that I was a really good speaker. They thought, 'Hey, you're a wonderful speaker and you've done great acting films like short films, why don't you speak for some people at U of T [University of Toronto]?' There, a representative of candidates saw me, and they're like, 'Would you like to speak? Would you like to work for us and help us get the message across?' And I was like, 'That's a perfect marriage.'

Caitlin Sometimes we talk about people being pushed and pulled into leadership roles; sometimes it's because people have negative experiences that make them want to make things better, or people have great experiences that make them want to continue that great work that people are doing. And it sounds like you had some of both types of experiences throughout your life that got you involved. Your work with the Centre for Addiction and Mental Health is not only spreading awareness about the need to improve supports for people with disabilities who have mental health support needs, but you're also providing some really important resources to help people who need it. Can you tell me about some of the work that you're doing now that you're most excited about?

Victor I'm super excited about the podcast, *IDD Get to Know Me*. We talk to plenty of researchers, clinicians, and people that are in the IDD world, and we get their perspective on how IDD works. I'm also excited about the Easy Reads I do with my fellow advocate advisors. And I cannot thank my wonderful partner, Julia, enough. She gets the guests, and she sits down with me and comes up with the questions. We create our questions together, and I cannot thank her enough.

Caitlin How are the podcast and the Easy Reads, helping people with disabilities who have mental health support needs?

Victor If you want to hear what's going on in people's lives through disability, you can listen to the podcast or read the Easy Reads. You can read about COVID and how it affects people's lives and how it was so damaging for so many people with special needs. Because remember, we did not have our programs during COVID, so many people were frustrated. The Easy Read provides information about how COVID works and the resources that you can reach. If you want to go to the doctor's, don't feel scared. These are the steps that you can take to get your shot. It's just an amazing process to have the Easy Reads.

Caitlin Is information, or lack of information, a big problem for people with disabilities?

Victor Most governments don't have enough information about people. We don't have proper funding, and we don't have the proper support we need. So, it was a really scary time when the government shut down and we were all in our little houses or apartments and we could not talk to anybody. It was really hard for most of us.

Caitlin If you had a magic wand, what would you change about the service system for people who need both mental health and disability services?

Victor The government, honestly. They're focused on the dollar, and it makes me frustrated to no end that we don't get the services that we have the right to have, like every other human being. We're human beings at the end of the day. We're not just this type of class and this type of class. We're all human beings and we all still have the right, the human right, to socialize, to be in relationships, and to be in programs that we like. It starts at the top. It starts with government leaders understanding what struggles we face every single day.

Caitlin What are some things that you do in your work to help people get passionate, or to start to care about making sure that people who have both disabilities and mental health support needs get the services they need?

Victor Just tell our stories. I know it's simple, but some people are really scared about sharing their stories, because they might feel ridiculed, but it's important to share your story, and it's important to care about people and to help people get the help they need.

Caitlin Do you think that there's a fear that people with disabilities have of talking about their mental health support needs? Like fear of stigma?

Victor A lot of times when you're labeled special needs, you don't get certain benefits that you have when you're 'normal,' so people are afraid of their unlabeled special needs. [They are afraid] the government might take away some of your benefits and then you're screwed.

Caitlin And some of those benefits are for mental health support needs?

Victor Mental health is health — let's not forget about that. And it's hard for people to express their emotions, because they're taught at a very early age to keep those emotions in and keep going. But if you show your emotions, if you show that you're vulnerable, people might care more. People are empathetic, and that's what most governments don't get. So, we're born with disabilities. We're vulnerable people, we're scared. We went through an epidemic, and look, we're stronger for that.

Caitlin You just talked about how people are taught that if there's a problem, you just move through it. You don't talk about it. Do you think that's true for everyone? Do you think that's especially true for people with disabilities?

Victor I think that's true for men. Men are taught you're not supposed to show emotion. But honestly, it's 2025. You're supposed to have off days, and you're supposed to feel empathy. It's normal to be brave, but when you need help, ask for help, and people are there with services to help you. You're not bigger than your problems. People can help you.

Caitlin Do you find that sometimes other people with disabilities or other people are surprised when you talk about things like emotions and mental health?

Victor Yeah, because I'm such a hyperactive kid. I like to play around, be goofy; but I get to a point where enough is enough. I need to talk about people who have special needs about how misrepresented we are.

Caitlin I think that showing vulnerability like you do is such an important example for other people. Like you said, it builds empathy. It helps people see other people's humanity. What else do you want to tell me about the work that you do?

Victor My colleagues and advisors and the workers are amazing. People complain that, 'Oh, I hate my job. I don't like this person,' but in the five years that I have worked here, I never had a colleague be mean to me. Everybody is just amazing, and everybody communicates. It's amazing people and amazing projects that we're doing. And I cannot say my lucky stars enough for the Center for Addiction and Mental Health.

Caitlin Right now, in a lot of organizations and in our field, people are pretty stressed; it can be a rare thing, even for people who are leading at every level, to really practice what they preach. What do you think makes it so that your organization can really live its values?

Victor We're just passionate. We're just passionate people wanting to change the world, change the stigma for people with special needs, for the better — we're just passionate. That's all it is.

Caitlin I'm going to ask you one more question about that, because I think that's so important for people who work in our field, who are really passionate, but have a really hard time building organizations, building cultures that do exactly what you're talking about, that make sure empathy and care are embedded in how they work together. What advice do you have for them?

Victor Lose your ego. Leave your ego out the door; forget that you're better than anybody else. Forget that you think that you work harder than anybody else. Just be yourself. Look at yourself and what you're doing, and remember, just lose your ego and it'll get you very, very far. You can make more friends if you just lose your ego and just are passionate about what you're doing.

Caitlin That's really good advice. Thank you, Victor.

This interview was shortened to accommodate limited space.
To read the complete interview, please visit: https://natleadership.org/perspectives.html

Victor Pereira *is a Patient Advisor at the Azrieli Adult Neurodevelopmental Centre. He is an expert in disability and mental health and has shared his lived experience and knowledge of promoting mental health for people with disabilities across Canada. Victor is an influential advocate and has partnered with the Centre for Addiction and Mental Health to create resources that bridge the gap between people with disabilities and health care systems. Contact Victor at lil_vic_fg@hotmail.com.*

Caitlin Bailey *is the Co-Director of the National Leadership Consortium. She holds a Ph.D. in Human Development and Family Science. Caitlin is passionate about enhancing leaders' skills and evidence-based practices in our field. Contact Caitlin at cbailey@natleadership.org.*

Humanizing Human Service Systems: A Small Piece of Dave Hingsburger's Long Legacy

By Amanda Rich

- Dave Hingsburger did many important things to support disability rights and improve disability services. He died in 2021.
- His work helped to change disability service systems and better support the dignity, freedom, and wellbeing of people with intellectual and developmental disabilities.
- Some of the messages in his work included:
  - Having control over your life is important to wellbeing. Behavior challenges are often a result of systems and services that are not working well.
  - The wellbeing of service providers is important to the wellbeing of the people they support.
  - People who work in disability support services need to be careful not to abuse power.
  - Systems are made up of people and people can change.
  - Restricting people's freedom makes them less safe.

In the Summer of 2021, the world lost David Hingsburger. Dave was an iconic author, clinician, sexuality consultant, speaker, thought leader, and much more in the disability rights and developmental disability services community. He was well known for his prolific writing, his sharp wit, and his commitment to speaking often uncomfortable truths about the disability service systems in an unflinching and unapologetic way. He did many things in his life, but a large part of his work addressed how systems of care, even those designed with the best intentions, could cause significant harm to people with developmental disabilities. Hingsburger discussed the role systems played in supporting and hindering people's wellbeing, mental, behavioral, and sexual health. As such, we at the editorial board of Bulletin saw it fitting to honor him in this issue by highlighting some themes of his work most relevant to the topic of mental health and intellectual and developmental disability services.

- **Wellbeing and dignity require having agency and control** in one's life. In his book "Behaviour Self!", Hingsburger described how often the source of people's mental, psychological, and emotional distress expressed through challenging behavior is a desire for greater agency and more control in one's life. Yet often the responses to challenging behavior of people with disabilities are greater restrictions.
- **"Inappropriate behavior" is often an understandable reaction to an "inappropriate system."** In his book Power Tools, Dave noted how it is always unethical to try to change a behavior without attempting to understand it. Behavior that is deemed "inappropriate" is often a response to a setting or system that is not working well for the person
- **The dignity and wellbeing of frontline staff and the people they support are intertwined.** Dave shared how often frontline staff are the people with the least amount of power within the organization but the greatest amount of power in the lives of the people they support.

- Supporting people ethically, in ways that promote as opposed to diminishing their wellbeing, requires providers to **be conscious of the ways power and control moves within organizations**. That requires that organizational leaders develop an awareness and responsiveness to how they share power with, as opposed to wield power over, front line staff and that they help staff develop an awareness and responsiveness to how they do the same to those they support. He wrote in the book Power Tools that, "*Feeling powerless makes it more likely that you will make powerful mistakes*" (p. 5).
- **Restricting access to consensual and healthy sexual expression is a form of sexual violence.**
- Abuse prevention requires access to healthy sexual expression, pride, and social connectedness. **Restricting people's agency,** in the form of limiting their opportunities for social connections, work, recreation, and/or information, **makes people less safe**. In his book *Just Say Know*, Dave describes how sometimes family and staff's response to the fear of abuse and victimization is the creation of a "prison of protection." The "prison of protection" inadvertently makes people with disabilities more vulnerable by limiting their access to caring networks of others, limiting their access to information needed to help them differentiate between needed and wanted intimacy and abuse and coercion, and limiting their access to opportunities that help to support joy and pride in their lives.
- **Disability pride** supports health, wellbeing, dignity, and safety. He noted in the article Healthy Sexuality: Attitudes, Systems and Policies that, "*The development of pride in difference was the starting point for healing in many minority communities*."
- Changing human service systems is as easy and as hard as changing the way humans think and act. He wrote, "When people talk about the 'system' they usually do so as if the system were concrete and non-human. This isn't the case; **the system is you and me**." (Just Say Know, p.11).
- **Being in human services is fundamentally about finding better ways of being human together**. Open Future Learning produced a video to celebrate National Direct Support Professionals Week and in it they read some of Dave's words. It read in part, "*Being in human services is cool because in essence you are paid to be human, paid to explore the commonalities in the human condition, paid to discover the incredible diversity of the human spirt.*"

You can learn more about Dave Hingsburger's life and work through his videos on Open Future Learning, his books on Diverse City Press, his blog Of Battered Aspect, other videos on the internet, and by talking to the people across the world who worked, loved and/or learned from him.

Amanda J. Rich *is the owner and CEO of Open Road Inclusive Community Consulting and the managing editor of the National Leadership Consortium Bulletin. Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at openroadicc@gmail.com.*

Grief Happens: Supporting People Through Loss

By Amanda Gee

- Loss and grief are universal experiences.
- People with disabilities often experience more loss throughout their life span.
- The basics of grief supports are informing, listening, and involving.

Grief is natural and usually resolves on its own.

Loss is a universal experience. No matter who you are, you will experience loss at some point in your life — loss from death of someone you care about, or loss of other important things. Grief is the emotional pain and longing that arises after a significant loss. Grief is most often associated with loss from death, but grief can come from all types of loss.

We are trained for a lot of things in this field. We learn all about different disabilities, standards of care, positive behaviour supports, ethics, rights, medications, and first aid, but rarely do we learn how to manage grief. When we enter this field, we typically don't think about loss and grief but in a health care profession, supporting people, it is bound to happen. Death will happen.

People with disabilities experience a lot more loss in their lives. Like all of us, they experience loss from death, but they are also more likely to experience a higher amount of loss due to the support people in and out of their lives, loss of home and family, loss of friends, loss of abilities, loss from not being able to achieve goals. They have often historically been sheltered from grief, which does more harm than good.

Here are some tips to support people with disabilities through grief:

- **Telling people about the death** — Be concrete by using real words like "died" and "dead" rather than "passed away." Make sure that you take as much time as they need to understand what is going on. We know understanding the concept of death is different for each person. Be clear and keep it simple and then answer whatever questions come up. Using visuals can be really helpful — show people a picture of the person who died while telling them if you can.

- **Allow for feelings** — Feelings are normal, and all feelings are valid. Let people feel and talk about it. Telling people not to cry or not to feel sad is not helpful. Feelings of anger or guilt can also come up — these are normal in the process of grief.

- **Involve people** — Ceremony is important in grief. Things such as funerals or memorials can be helpful in the grieving process. Sometimes attending a funeral or memorial is not possible for a multitude of reasons but maybe there is an option to attend virtually. Another option is to do something within your organization to acknowledge the death as a group, like holding memorial or celebration together, coming together as a group to share, or making cards for the family.

- **Continue to talk about it** — Talking about it is especially important when working with people who do not communicate traditionally, who maybe don't have the words to express their sadness, their longing, their questions. It's okay to keep talking about the person who died, sharing memories, and acknowledging their absence.

- **Use creative ways to process** — Creative arts therapies can be amazing tools for expressing and processing grief. Art and music can be great for getting out feelings and thoughts that cannot be expressed through words.

- **Remember that processing grief is different for everyone** — Everyone processes and manages grief differently. Sometimes people with disabilities have experienced so much loss in their lives that it hits harder, and they can hold on to grief longer. Grief can also bring up all the feelings of loss we have felt in the past. So, a new loss, or even someone else's loss, can bring up lots of intense emotions for someone. Alternately, someone can seem "okay" and still be grieving because they have been through it so often.

- **Ongoing support** — It is good to create a culture in an organization that acknowledges loss and supports grief. A grief group can be a helpful way to create peer support, and something like a memory wall or garden gives people a place to feel connected.

Here are some other things for the organizations to consider around loss, death, and grief:

- **Tell people the facts** — Tell your staff as soon as possible - don't wait, don't hide it. Make sure there is time for people to hear it, to digest it, to ask questions, and to take it in. There isn't ever a "good time." They may have already heard rumors, stories, but don't assume people know.

- **Listen** — With grief, people want to be able to tell their story, they want to be heard, they want to be able to share thoughts and feelings and feel supported. Provide that space for people to talk and to share. Let staff and clients know that there is a safe space to talk.

- **Access resources** — If someone died within a program in your organization in a tragic way bring in the professionals. You could hire a grief counselor to come in for a day. If the organization has an employee assistance program, then remind staff about it. Give them easy access information.

- **Moving on** — In a residential setting, that now open bedroom will probably need to be filled quickly — be sensitive and gentle about this. Memorialize the individual in other ways in the home, such as through photos.

- **Staff Turnover** — When at all possible, if a staff or support person will be leaving the job give a bit of time for processing and goodbyes.

Typically, grief diminishes with time — it doesn't necessarily go away but it becomes easier to manage. Most people go through this process naturally with the support of caring people around them. Seek professional help if the grief is not diminishing at all after months and the individual is not able to return to their regular daily activities. Providing a supportive environment within an organization creates a good foundation for when grief does happen.

To read more from Amanda about the topic of practices to support mental health in the disability field during times of grief, check out these other articles:

Grief:
When You Are At A Loss After A Loss
[Link: sss-vol-1-issue-5.pdf]

Good Grief:
Supporting People through the Grieving Process
[LINK: sss-vol-11-issue-6-ENGLISH.pdf]

When Death Happens at Work:
Working With and Through the Grieving Process
[LINK: sss-vol-8-issue-10-ENGLISH.pdf]

Amanda Gee *is a Registered Counseling Therapist (RCT) and a Registered Canadian Art Therapist (RCAT) and works as the Client Support and Education Specialist at DASC in Dartmouth, Nova Scotia. For the past 20 years Amanda has worked as a therapist supporting the mental health of people with disabilities and is passionate about grief support. Contact Amanda at clientsupport@dasc-ns.ca.*

Improving Services for People with Co-Occurring IDD and Mental and/or Behavioral Health Support Needs: Lessons Learned from Research in Washington State

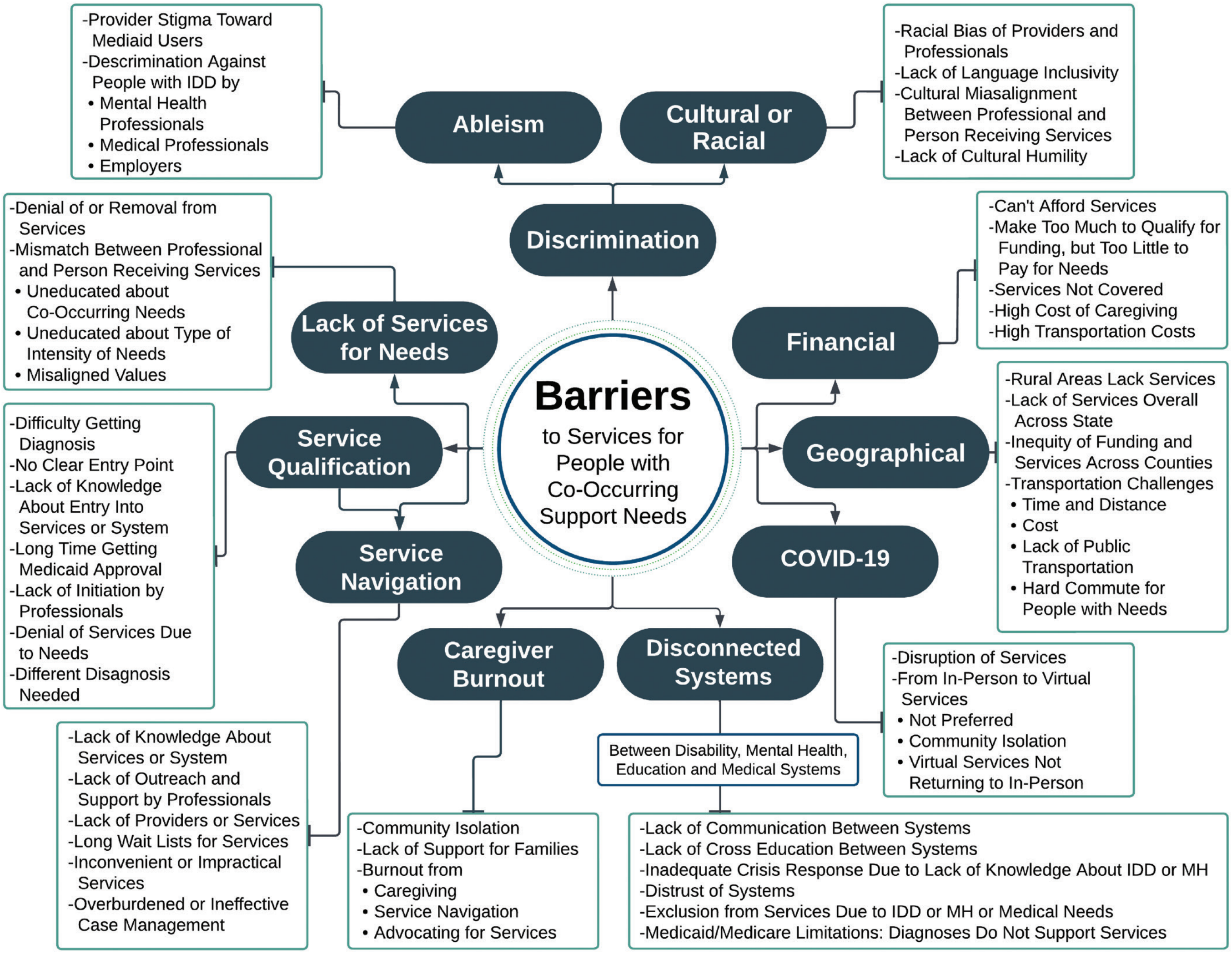
By Cory Gilden

- The National Leadership Consortium did a study in Washington state about what helped and what got in the way of people with IDD accessing mental and behavioral health services.
- The researchers got information by interviewing people with lived experience and conducting a survey.
- They found nine major barriers to accessing care.
- Some of the barriers included: discrimination, location, lack of qualified service providers, caregiver burnout, and difficulty navigating between IDD and mental health service systems.

The National Leadership Consortium conducted a mixed-methods study in Washington state during the summer of 2024 investigating current barriers and facilitators to disability and mental/behavioral health services for people with co-occurring IDD and mental and/or behavioral health needs. The study collected data through interviews with 19 people with co-occurring support needs and family members of people with co-occurring support needs, a focus group of eight self-advocates with co-occurring support needs, and a statewide survey of 398 people with co-occurring support needs and family members or guardians of people with co-occurring support needs. We found in this study that many barriers exist for people with co-occurring support needs to get appropriate support, and we know from our work with leaders across the country that many of these issues are not state-specific, but systemic problems in the field.

What Does the Research Say?

The results of the survey, interviews, and focus groups aligned related to the barriers identified by participants. The barriers fell into nine main categories: discrimination, financial, geographical, COVID-19, lack of services for needs, service qualification, service navigation, caregiver burnout, and disconnected systems. Study participants noted *systemic challenges* like long waiting lists and ineffective case management, *service challenges* like regional disparities in service availability and lack of communication between different types of services, *organizational challenges* like workforce shortages and mismatches between professionals and person being supported, and *resource challenges* like lack of public transportation and digital equity gaps.



Thematic Map of barriers to services for people with co-occurring support needs from interviews with people with IDD and family members of people with IDD in Washington State

Results of the survey were also analyzed to examine differences between historically underserved populations (e.g., BIPOC, live in a rural area, live on an Indian Reservation, low-income, LGBTQ+, etc.) and the general IDD population. People with IDD from historically underserved populations were found to be more likely to face increased barriers to services related to cost, scheduling, distance, and transportation, and more likely to say that IDD and mental/behavioral health providers only respect their culture, religion, and values “a little bit.” People from historically underserved populations were also about 50% more likely to rate their IDD services and mental/behavioral health services as “excellent,” showing they are more dissatisfied with their services.

What Does It Mean for Our Field?

Results of the survey were analyzed further to examine differences between IDD services and mental/behavioral health services. About one-third (35%) of survey respondents rated the quality of their IDD services as “fair” or “bad” and slightly more people (37%) rated the quality of their mental or behavioral health services as “fair” or “bad.” Similarly, about one-third (31%) of people rated their overall satisfaction of their IDD services as “fair” or “bad” and one-third (36%) rated their overall satisfaction with their mental or behavioral health services as “fair” or “bad.” Additionally, about 30% of people shared that their disability and mental or behavioral health providers do not communicate with each other or work well together.

A positive light in the results was that people felt that their IDD service providers respected their cultural background, religion, and/or values more than their mental/behavioral health providers, as well as aligning with their background and values more. While this finding seems to indicate more cultural sensitivity in the IDD field than the mental/behavioral health field, with one-out-of-three people feeling dissatisfied with their IDD and mental health services and how they work together, there is a lot of room for improvement.

What Does It Mean for Me?

While this recent study was conducted in Washington, there are many takeaways for service providers across the country to better support people with IDD and their mental/behavioral support needs.

- Make systems that support people with disabilities and mental or behavioral health support needs work together. Many people shared that it is hard to get services for having a disability and services for having mental health support needs. Many support coordinators, support staff, and medical professionals do not understand how to support both types of needs. More training and working together across systems is needed.
- Make sure there are enough staff to support people with disabilities and mental and behavioral health support needs. Make sure that staff have the training and support they need to provide good services.
- Make sure there are enough services for people with disabilities and mental and/or behavioral health support needs. Make sure that people living in rural areas have the transportation and services they need.
- Train and support service coordinators, support staff, and medical professionals to support people with disabilities and mental and behavioral health support needs. Make sure that staff use person centered practices to provide great services.
- Help people who live in institutions because of their mental or behavioral support needs live in the community. Help community service providers so that they can provide services that people need.
- Support advocacy for better mental and behavioral health support for people with disabilities. Hold an event so that people can come together to talk about the next steps to improve services for people with disabilities and mental and behavioral health support needs.

Want to learn more about this study? Read the full report at https://www.natleadership.org/Reports/EnhancingServicesforPeoplewithCo-OccuringSupportNeedsinWashingtonState.pdf

Cory Gilden *is the Research and Evaluation Manager of the National Leadership Consortium. Cory holds a Ph.D. in Urban Affairs and Public Policy and works with local and national organizations, conducting research and advocating for people with disabilities and their families. Contact Cory at cgilden@natleadership.org.*

Caregiver Mental Health:
A Review of Research Findings

By Lynda Lahti Anderson and Sandra Pettingell

- The lack of adequate support services and the direct support workforce crisis means family members are providing more support for their loved ones with IDD.
- Providing support to a loved one with IDD can make it more challenging to balance responsibilities, including taking care of themselves.
- There is a need for increased caregiver support, including respite services.

Most people with intellectual or developmental disabilities (IDD) live with their families. This includes 61% of those who receive paid help. Family members assist with daily tasks and personal care. They help with community outings and transportation. They also support decision-making, money management, medical care, and offer emotional support. Many families provide most of the support their family members need. Families say they are offering more help since they cannot find direct support professionals (DSPs).

The Family and Individual Needs for Disability Supports survey (FINDS), a survey of 3,000 family caregivers, asked about their experiences. Most caregivers (70%) live with the person they care for. Many are parents (85%), and many (84%) are 45 years or older. Over half (55%) have cared for more than 20 years. More than half (60%) said the DSP shortage affected their family members' provided services.

Caregivers reported challenges in caring for their loved ones. For example, nine out of 10 said caregiving affected their work. Many were late or left early (70%), reduced their hours (45%), or worked less than they wanted (51%).

Most caregivers agreed that several supports would help them balance work and other duties. These include:

- A tax credit for caregiving costs (84%)
- Payment for providing support (95%)
- Paid time off (78%)
- Help with navigating education (IEPs) and services (81%)

Family caregivers often face high stress. About 67% reported significant stress. Nine out of 10 said caregiving increased their stress. A major source of this stress is finding necessary help. For example, 67% of caregivers had trouble finding quality in-home support. Also, 60% found it difficult to get temporary help, like respite care. Caregivers struggled to get enough rest (43%). They also had trouble managing health issues (35%). Many found it hard to meet personal needs, like time for themselves or exercise (47%). People with lower stress levels often rated their health as "very good" or "excellent." In contrast, those with higher stress did not report the same.

Three key factors were identified that help caregivers manage stress and build resilience:

- Having social support
- Good quality of life
- Positive perspectives

For example, 48% of caregivers said caregiving helped them form new life values. Also, 35% noted it improved family relationships. Caregivers with strong social support and a good quality of life felt healthier. Almost 40% were more willing to seek help from others. More than half (57%) spent extra time at home with family. They made new friends, found jobs, and explored interests in IDD. A good quality of life was also linked to lower stress levels.

Caregivers who use positive thinking and coping strategies show greater resilience. Social support also matters. Caregivers with strong networks feel less stress and more satisfaction. Many caregivers in the study reported that their quality of life improved. They felt closer to others and appreciated life more, even with the stress.

These findings matter for caregivers, service providers, and policymakers in order to support caregivers effectively.

Policies and programs working toward improving mental health and support strains of caregivers should focus on:

- Financial assistance
- Increasing workplace flexibility
- Enhancing Medicaid support for family caregivers
- Providing mental health and emotional support, such as support groups and stress management programs
- Improving the respite care system so caregivers have time for self-care
- Providing support on how to navigate complex systems

Family caregivers of individuals with intellectual or developmental disabilities face many challenges, including high stress and difficulty finding necessary support. While caregivers are trying to balance work, personal life, and caregiving duties, the shortage of direct support professionals is making their role even harder. However, support such as financial assistance, paid time off, and access to mental health resources could make a big difference. Strong social support, a positive outlook, and a good quality of life are also key to helping caregivers cope and feel less stressed. Policymakers and service providers need to focus on creating policies that provide more support for these caregivers, ensuring they can continue to care for their loved ones while also taking care of their own wellbeing.

Lynda Lahti Anderson *holds a Ph.D. in Rehabilitation Science focusing on health disparities for people with ASD/IDD from the University of Minnesota. Lynda's interest in family caregivers comes from her personal experience as a caregiver and from working with families in a variety of settings. While at the Institute on Community Integration, she has working on training and research projects related to family caregivers and their experiences. Contact Lynda at lla@umn.edu.*

Sandra Pettingell *is a Research Associate at the University of Minnesota Institute on Community Integration. She holds a Ph.D. from the University of Minnesota. Her expertise is in research methodology and statistics. She enjoys helping provider organizations make data driven decisions that enhance their staff's work experience and improve the quality of the supports and services they provide. Contact Sandra at erick100@umn.edu.*

Peer Mentorship and Mental Health: An Interview with Peer Mentor Brittany Ellis

By Amanda Rich

Bulletin staff talked with Brittany Ellis, an IDD Peer Support Specialist at JCI of North Carolina, about her thoughts on the role of peer-mentors in supporting the mental health and wellbeing of people with disabilities.

- Peer mentors are people with a particular lived experience, like having a developmental disability, mentoring others with a similar lived experience.
- Though peer mentors aren't a replacement for mental health treatment, they can help support positive mental health.
- Peer mentors can often understand certain challenges related to living with a disability differently than other types of mentors.
- Peer mentors can help people develop new strategies and skills for supporting their mental health.

Research shows that people with intellectual and developmental disabilities often struggle with mental health concerns and face barriers in accessing effective mental health care. Peer mentors are people with a particular lived experience guiding, coaching, and providing support to others with a similar lived experience. Peer mentorship has been shown to reduce symptoms of depression and improve self-esteem in young adults with learning disabilities and ADHD, improved social connectedness, positive disability identity development and quality of life among Autistic adolescents and adults, and improved and self-determination and self-advocacy skills among adults with intellectual disabilities.

What exactly is the role of a peer mentor?

The role of peer mentor is to guide and encourage the person you are working with. You help to give them the tools they need to lead self-determined lives and be able to advocate for themselves and for others. I think what it offers that other types of mentorships might not is being able to share and use your experience to help the other person. I was talking with an individual yesterday. They were telling me about criticism they were receiving from their parents for not doing things like the dishes at a certain time. I could tell there was something else there from my own experience and so I asked them if they felt upset because they felt that part of the criticism was related to their parents feeling like they couldn't remember or understand because of their disability. There was a shared experience and being able to talk about disability with someone who understands where they are coming from and how things like stigma might come into play in certain situations where others without a disability might not see or understand it.

What do you see as some of the challenges that people with disabilities, especially intellectual and or developmental disabilities, face related to their mental health or mental health care?

For one, it’s just access to information and support. Even in terms of open resources, like on YouTube, there are resources for kids with disabilities and adults without disabilities. People with disabilities do grow up and yet there is not a lot out there for them. There are not many resources on mental health or accessing mental health care in plain language. There are not a lot of resources run by people with intellectual and or developmental disabilities for people with IDD about mental health or how to access support themselves. Finding and getting help can be hard.

What do you think might help address the challenges?

We need more resources that are designed by people with disabilities for people with disabilities about mental health in general and accessing mental health care. That would be beneficial to people with disabilities. It would involve recruiting people with disabilities to help create the resources and getting input on what would be important topics and getting the information out there.

How do you think peer mentors help to support people’s wellbeing?

Peer mentorship is not therapy, but I think in a sense, it’s its own type of therapy session, being able to talk about shared experiences and being able to open up to someone you can trust and who has shared those same challenges. Peer mentorship can be like a safe space to work on challenges. We can talk about coping skills and how to use them. We can work together to find things to put in our toolboxes to help with emotions, feelings, and figuring out problems.

What role might peer mentors play in helping people with IDD better access mental health support?

I think peer mentors can take what they’ve learned and pass it along to the individuals that they work with. Any resources I have used that were helpful and might be beneficial to the person, I can share. Peer mentors can help them find ways to cope or whatever the struggle might be to give them other ideas. I think one of the things I talk a lot about to those I’m mentoring is the importance of self-care. I think it’s important to find things that you enjoy doing and I tell them to find something that they enjoy doing, spending a little time on themselves every day. I think that’s important for everybody. We’re all different and we all have different things, different coping skills or different ways of self-care and trying to find what helps you the most and what you enjoy doing is important.

As a peer mentor, what do you find helpful in supporting your well-being and your mental health?

For me, and I tell the people I work with this as well, it’s music. Music could be very beneficial. I’m a big music lover myself. I feel like there’s always a song or genre or type that could fit any mood that you’re in. I think having a good support system is important as well. Having somebody that you can trust or just vent to in person or on text is a way to work through however you are feeling.

What do you think peer mentors need to best be able to support those they are working with as it relates to their wellbeing?

I think one thing that would be helpful are ways and ongoing opportunities to connect with each other and to work with each other to find different ways of doing mentorship. It helps to learn from each other about what works for them and alerting one another to resources. We need more ways to learn from one another.

What is one thing that you learned or has impressed you about peer mentorship?

One of the biggest things I've learned when I'm trying to guide the person that I'm mentoring is that at the core of it is loving yourself. When you love yourself, you are more willing to try new things and take risks. That adds confidence. Then when you're more confident, it's easier to advocate for yourself and make choices for yourself. Kind of like a big circle. Everything seems to come down to how you think and feel.

Brittany Ellis *is an IDD Peer Support Specialist at Johnston County Industries, an NIP Inclusive Recreation Specialist, and an ALP alumni. Brittany is passionate about helping others lead self determined lives. Contact Brittany at Brittanyhellis52@yahoo.com.*

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Managed and Integrated Care for People with IDD: Mental Health Care is Key to Whole Person Health

By Dana Lasenby and Christine Burk

- The stigma around mental health or misunderstanding mental health needs sometimes leads people with IDD to not get the mental health support they need.
- Managed care aims to combine physical and mental health care information in one place, which is helpful for people with disabilities who often have more than one diagnosis.
- Managed care encourages collaboration between organizations, providers, and people with IDD to provide better services.

Mental health care is essential healthcare. Recognizing and normalizing this critical public health conversation ensures that physical and mental health are integrated and inclusive of the whole person, their family, and their social, emotional and economic wellbeing.

The Centers for Medicare & Medicaid Services (CMS) describes managed and integrated care as *an organized approach to treatment that coordinates services across multiple healthcare providers and disciplines*. This model is particularly beneficial for individuals with intellectual and developmental disabilities (IDD), as it fosters comprehensive and person-centered care.

Good mental health promotes hope, resilience, and self-determination, which are critical to helping individuals with IDD pursue and achieve their goals. Managed care models that integrate physical and mental health services enhance the quality of life for individuals by ensuring a holistic approach to healthcare.

At Oakland Community Health Network (OCHN), managed care coordination is built on the principle of inclusivity — ensuring that the voices of individuals receiving services guide the development of their care plans: "Nothing about us, without us." This philosophy ensures that people with IDD are empowered to shape their healthcare experiences, reinforcing their autonomy and dignity.

As the Prepaid Inpatient Health Plan (PIHP) for Oakland County, Michigan, OCHN manages public health services for approximately 30,000 residents, encompassing intellectual and developmental disabilities, mental health, and substance use disorder services. This role involves direct collaboration with individuals, families, service providers, and stakeholders to build a responsive and person-centered care system.

Engaging individuals with IDD in decision-making is necessary for effective managed care. OCHN solicits feedback through its Citizens Advisory Council (CAC), Recipient Rights Advisory Committee (RRAC), surveys, community forums, and ongoing provider meetings. However, gathering input is only the first step — what matters most is the action taken in response.

The foundation of quality managed care is built on meaningful engagement, data-driven decision-making, and continuous improvement. This requires a commitment to asking the right questions, responding transparently, and implementing solutions that enhance care quality. One of the key benefits of the PIHP model is its local oversight, which ensures a direct connection to recipient rights and community needs.

A holistic approach to managed care is vital for individuals with IDD, as their health conditions often involve complex interdependencies. Service providers must recognize the interplay between primary and secondary diagnoses, ensuring that both receive equal attention. According to the CDC, adults with disabilities experience mental health challenges nearly five times more frequently than those without disabilities. These challenges are linked to higher rates of chronic illness, increased healthcare utilization, and barriers to daily functioning.

Unfortunately, the stigma surrounding mental health can prevent individuals with IDD from seeking the care they need. In some cases, healthcare providers may misattribute symptoms of mental illness to a person's disability rather than recognizing them as independent conditions. Addressing these barriers requires vigilance in listening to individuals and leveraging healthcare data to detect and respond to potential crises before they escalate.

Shared electronic healthcare records are vital for improving care coordination and provider communication. Approximately five years ago, the Michigan Department of Health and Human Services (MDHHS) implemented CareConnect 360 (CC360), an electronic healthcare data-sharing platform to enhance integrated care management. CC360 has demonstrated significant positive outcomes, including a 32% reduction in emergency department visits and a 71% decrease in hospitalizations among individuals receiving shared care planning. By utilizing data-driven insights, OCHN successfully manages high-acuity cases with promising results. Proactive and preventive healthcare are core principles of effective managed care. By leveraging real-time data and fostering collaboration between service providers and managed care principals, OCHN ensures that individuals with IDD receive timely and appropriate care.

Understanding care from the perspective of direct care providers and managed care organizations guides funding that leads to rate equity, ensures compliance with regulatory requirements, and improves service delivery. Open and transparent dialogue remains crucial. Effective leaders recognize the importance of collaboration and accountability in delivering high-quality, person-centered healthcare services and sustainable positive outcomes.

At its core, managed care is about partnership — between organizations, providers, and the individuals being served. By prioritizing advocacy, community inclusion, and integrated healthcare solutions, OCHN and its providers stand united in their commitment to ensure that individuals with IDD receive the comprehensive, compassionate care all deserve.

Dana R. Lasenby *is the Chief Executive Officer and Executive Director of the Oakland Community Health Network. Dana is a Behavioral Health Care Executive and Limited Licensed Psychologist with more than 25 years of experience in the public and private sector of the behavioral healthcare industry. Her unique set of administrative, clinical, and operational skills are critical to the management of one of Michigan's largest public community mental health systems. Contact Dana at* lasenbyd@oaklandchn.org.

Christine Burk, MAC, *is the Chief of Staff at Oakland Community Health Network. Christine Burk has more than 30 years-experience in public and community relations, crisis management, community education, and legislative consultation. She has dedicated the last 15 years of her career working in the public behavioral health space, supporting advocacy initiatives for persons served. Contact Christine at* burkc@oaklandchn.org.

What We're Reading, Viewing, and Listening to

Title: How the Mental Health Crisis Impacts Americans with Disabilities

Author/Editor: The Arc of the United States and NBC News (2024)

Description: In this brief NBC news clip, the hosts interview Leigh Anne McKingsley, the Senior Director of Criminal Justice Initiatives for The Arc. In the interview she discusses some of the challenges people with disabilities face in accessing mental health support and what is being done by The Arc and other organizations to navigate these challenges.

Title: Loud Hands: Autistic People Speaking

Author/Editor: Julia Bascom (2012)

Description: This book presents a collection of essays written by and for Autistic people. The book covers many topics related to neurodiversity. Some of the essays describe the harm they experienced relating to behavioral health services. It is a powerful and compelling book.

Title: Barriers to Care for People with Co-Occurring Mental Health Disorders and Intellectual and Developmental Disabilities

Author/Editor: Healthy Minds Policy Initiative (2024)

Description: This newsletter describes several of the barriers that people with IDD and co-occurring mental health disorders face in accessing mental health care and provides links to supporting research.

Title: How State Agencies Can Anticipate and Meet the Needs of Adults with Intellectual and Developmental Disabilities and Their Aging Caregivers

Author/Editor: Centers for Medicare & Medicaid Services (CMS) (2023)

Description: This policy brief provides information, research, and resources on how state Medicaid and partner agencies can design and deliver services to both meet the needs of adults with IDD and their caregivers. A section of this resource describes better coordinating mental health support and IDD services.

Title: The Edge of Compassion

Author/Editor: Francoise Mathieu/Ted Talk (2018)

Description: In this Ted Talk, Secondary Trauma Specialist Francoise Mathieu discusses the challenge of sustaining empathy and compassion to both oneself and others and helps those in support provision or caregiving positions find the balance between empathy for others and personal wellbeing.

Title: Reducing Compassion Fatigue and Secondary Traumatic Stress and Burnout: A Trauma-Sensitive Workbook

Author/Editor: William Steele (2019)

Description: This book provides a comprehensive overview of the emotional challenges helpers and organizations face in relation to their work. It also provides worksheets and interactive activities to help the reader identify and respond to their self-care and mental health needs.

Title: The Compassion Fatigued Organization: Restoring Compassion to Helping Professions

Author/Editor: Michelle Graff (2020)

Description: This book offers a review of research and practical tips to help human service organizations build resilience and cultivate compassion within their organizations.

Title: Why We Need Mental Health Professionals with Disabilities

Author/Editor: Ashley Mohesky, The Mighty (2023)

Description: In this newsletter, Ashley Mohesky describes the challenges people with disabilities often face in accessing mental health care and describes why it is important to develop more mental health practitioners who have lived experiences of disability.

Title: Power Tools

Author/Editor: Dave Hingsburger (2000)

Description: In this practical, quick reading book, Dave Hingsburger describes how power moves through disability service organizations and the impact it has on the wellbeing of those using and providing services.

Upcoming Events

May - August 2025

The Keys to Leadership Workshop Series is a Five Part, Virtual Workshop held via Zoom. The Series consists of five 3-day workshops, with the first series The Challenging Side of Leadership beginning in April 2025. Attend one or all (or any combination) of the workshops below. To learn more or register, visit https://natleadership.org/KLWS.html.

- The Human Side of Leadership (May 2025)
- The Business Side of Leadership (June 2025)
- The Data Side of Leadership (July 2025)
- The Relational Side of Leadership (August 2025)

July 13-18, 2025

The Summer Leadership Institute will be held July 13-18, 2025 in-person in Newark, Delaware, at the University of Delaware. Applications are open now, Visit https://natleadership.org/week-long-institute3.html for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability, a Direct Support Professional, or a leader who works for a state department of developmental disabilities within the United States (Gary Smith Scholarship funded by NASDDDS) you can apply for scholarship support to cover tuition and some travel and hotel costs!

November 9-14, 2025

The Fall Leadership Institute will be held November 9-14, 2025 in-person in San Diego, California at the San Diego Regional Center. Applications are open now, visit https://natleadership.org/week-long-institute3.html for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability or a Direct Support Professional you can apply for scholarship support to cover tuition and some travel and hotel costs!

Applications will be opening soon for the following Programs:

The Workforce Innovations Leadership Institute in partnership with NADSP (July 20-23, 2025 in Newark Delaware, at the University of Delaware)

If you'd like to be notified when we open registration or applications for future trainings including the Leadership Institutes listed above, please add your name to the list at https://tinyurl.com/y3mpzz29.

Contact Us: https://natleadership.org/bulletin • bulletin@natleadership.org

If you have any trouble accessing the referenced material, please email Amanda J. Rich at openroadicc@gmail.com.