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The Intersection of Mental and Physical Health Impacting our Communities: Part 2

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Positive Approaches Foreword

"In essence, Positive Approaches is a worldview, in which all individuals are treated with dignity and respect, in which all are entitled to Everyday Lives."

—Beth Barol, 1996

The first issue of the *Positive Approaches Journal* was published in summer 1996 and focused on four domains: environment, communication, assessment, and "hanging in there." In the 29 years since that first edition, we have rebalanced our human services system so that most people are served in community versus facility settings. During this time, we have also witnessed significant advances in our understanding of trauma, brain development, genetics, and treatment options. In spite of these advances, the lessons from that first edition of the journal still hold relevance for us today because, as a system, we still face challenges in supporting people with co-occurring intellectual or developmental disability and a serious mental illness to live Everyday Lives.

As our service systems continue to move away from institutional and congregate care and toward supporting people to be fully engaged in their communities, the need to revive the *Positive Approaches Journal* became clear to us. People who have dual diagnoses face some of the greatest challenges for true inclusion and being connected with their communities. We need to work together to develop best practices and appropriate services and supports. The *Positive Approaches Journal* is part of a broad effort to build this capacity and support best practice in service delivery for people with dual diagnoses. The *Journal* will also allow us to share, communicate and collaborate as we address this very important issue.

We are eager for the submissions that will come from practitioners and theorists here in Pennsylvania that will drive innovation at all levels in our service systems. It is truly very exciting to begin publishing the *Positive Approaches Journal* again, and it is with great pleasure that we present to you Volume 13, Issue 5.

Kristin Ahrens
Deputy Secretary
Office of Developmental Programs

Jennifer Smith
Deputy Secretary
Office of Mental Health and Substance Abuse Services

Positive Approaches Journal Mission Statement

To improve lives by increasing capacity to provide supports and services to individuals with mental health and behavioral challenges, intellectual disabilities, autism, and other developmental disabilities, using the guiding principles of Everyday Lives and the Recovery Movement.

Through case studies, articles, interviews, and related academic sources, *Positive Approaches Journal* will strive to feature resources, observations, and advancements that are relevant and timely to professionals and supporters.

Introduction

This issue of the Positive Approaches Journal, "*The Intersection of Mental and Physical Health Impacting our Communities: Part 2*" continues the theme of the previous issue in exploring and emphasizing the importance of the balanced pursuit of physical and mental wellbeing. If you have not yet had the chance to view the previous issue, Positive Approaches Journal, Volume 13, Issue 4, I encourage you do so.

The Office of Developmental Programs (ODP) and the Office of Mental Health and Substance Abuse Services (OMHSAS) is grateful for the contributions to this issue from subject matter experts from within Pennsylvania as well as from several other states. The editorial staff of the journal continues to view this publication as an important tool as we seek to ever-expand capacity, support health equity, and promote access to an Everyday Life. The diversity of topics in this issue, to me, reflects the multifaceted needs and considerations important for the pursuit of comprehensive wellness. Far from being a specific blueprint of supportive approaches, please view this issue and its previous Part 1 as an opportunity to deepen an appreciation for complexities of wellbeing and an invitation to continue the conversation beyond these pages.

Gregory Cherpes MD, NADD-CC
Medical Director, Office of Developmental Programs

June Resource Discoveries:

Health Professional Shortage Area

Access to quality health care is a critical issue for people with Intellectual and Developmental Disabilities (IDD). Research finds that people with IDD often have complex mental and physical health care needs, and experience higher rates of comorbidities like obesity, diabetes, gastrointestinal issues, and sleep problems.[1] People with IDD also have higher rates of co-occurring mental health conditions like anxiety, depression, and Post Traumatic Stress Disorder (PTSD) compared to people without IDD.[2] Prior research estimates range from 37%-65% of people with IDD have a co-occurring mental health condition.[2] People with IDD use preventative care less frequently and rely more on emergency departments (EDs) compared to those without IDD. Additionally, people with IDD have higher rates of emergency psychiatric service utilization.[2] Adults with IDD also have higher annual health care costs than adults without IDD.[1] Currently in the United States access to medical care is being limited by a shortage of health care providers for physical and mental health.[3] The Health Resources and Services Administration (HRSA) designates geographic areas that lack access to health care due to shortages of care providers as Health Professional Shortage Areas (HPSAs). People living in HPSAs generally have greater unmet health care needs, and are at increased risk of preventable hospitalizations, chronic disease, and death.[3] The high rates of comorbidities combined with living in an HPSA can contribute to worse health outcomes for people with IDD compared to people without IDD.

Living in an HPSA may exacerbate the risks of poor mental and physical health outcomes among people with IDD. HPSAs tend to be in rural areas, have larger Black populations, lower employment levels, higher concentrations of lower-income individuals, individuals who are in worse physical and mental health, and more likely to be covered by public insurance.[3] HPSAs reduce medical office visits for both White and Black people, however the effect is nearly twice as large for Black people.[3] As stated in the previous Data Discoveries article, across all age groups, a higher percentage of Pennsylvanians with IDD live in a mental health professional shortage area compared to people without IDD. Additional disparities are found across race/ethnicity and disability status. For example, 3.6% of Black people with IDD live in HPSAs compared to 3.1% of Black people without IDD. The disparity is even greater for people with IDD who identify as more than one race, 11.5% live in an HPSA compared to less than 1% of people without IDD.

In Pennsylvania, investments are being made to strengthen the state's rural health care workforce to improve access to care. Presently, rural communities are especially affected by the health professional shortages, where there is only one primary care doctor for every 522 residents.[4] Rural Pennsylvanians have less access to health care and must travel further distances to see their doctors.[4] Investments to support rural hospitals to prevent service cuts, and the expansion of the Primary Care Loan Repayment Program, which offers loan repayment for health care providers that serve rural communities, are included in the upcoming budget proposal.[4]

Another potential solution to the shortage of primary care providers is to allow Physicians Assistants (PAs) and Nurse Practitioners (NPs) to provide more primary care services. The US is projected to have a surplus of NPs and PAs in 2037 which may alleviate the shortage of Primary Care Providers.[5] Investing in peer support programs can help alleviate the shortage of mental health providers. Growing availability of telehealth can address some of the geographic disparities in access for rural areas by allowing people to seek care across a larger area.

Given the complex medical needs of people with IDD, ensuring access to quality and continuous health care is crucial. The ASERT resource dashboard below provides key resources for finding and choosing health care providers to assist providers, individuals, families, and communities.

ASERT Resource Dashboard

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Pica and Lead Exposure in Pennsylvania's Children

Julia Kaya

Pennsylvania health care providers, especially pediatricians, should have an increased awareness of the potential interactions between pica and lead poisoning in the populations they serve. This awareness should increase vigilance in the care of young children with risk factors for either condition.

Pica is an eating disorder where people consume non-nutritious, non-food substances.[1] While mouthing non-edible substances is considered normal to some degree in babies and toddlers, children with pica exhibit a persistent, compulsive urge to consume non-food substances.[2] Pica affects approximately 3.5% of children in the United States, but is especially prevalent in children with autism spectrum disorder (23%) and is also associated with developmental and intellectual disabilities.[3] Pica is most commonly seen in children between the ages of 1 and 6 years, a time when curiosity and oral exploration are part of normal development. This stage also marks a critical period for brain growth, making lead exposure especially dangerous.

Pica has historically been under-diagnosed, and its etiology is still poorly understood. The association between pica and iron deficiency is, however, well-known, with many researchers and clinicians believing that iron deficiency induces pica.[4-5] Unfortunately, iron deficiency is also a known risk factor for lead poisoning, because individuals with iron deficiency absorb lead from the gut more efficiently.[6] Even low-level exposure to lead can cause intellectual, behavioral, and academic deficits[7], and intellectual disabilities are associated with pica.[3] Because pica and childhood lead poisoning share many of the same risk factors, these conditions can create a self-sustaining cycle with permanent repercussions.

According to data from the Centers for Disease Control and Prevention (CDC), Pennsylvania is one of the states with the highest percentages of children with blood lead levels above the reference level. This could be influenced by factors such as housing age, industrial history, and public health initiatives.[8] Among homes built before 1940, 87% had some lead paint. Although lead paint was banned in the United States in 1978, 24% of homes built between 1960 and 1978 had some lead paint.[9] Pennsylvania has the fifth most housing stock built before 1950 in the nation, meaning there are abundant opportunities for children to encounter lead paint.[10] This is especially true for children in families with low socioeconomic status who are more likely to live in older homes.[11] While lead paint is the supposed primary source of lead exposure in Pennsylvania, other sources of lead exposure include toys, ceramics, and drinking water when that water has flowed through older lead plumbing or pipes where lead solder has been used.[10]

Children with pica in Pennsylvania often eat paint chips from walls or windows, chew on ledges and windowsills, or consume soil from just outside their homes. All of these are potential sources of lead consumption. Peeling or chipping paint can either contain lead itself or pull lead from older layers of paint.[12] Windowsills and frames are common sources of lead in older homes, as lead paint was once used primarily for high-contact areas. Lead paint outside the home can be leached into nearby soil by precipitation.[13]

The CDC uses a blood lead reference value of 3.5 micrograms per deciliter (µg/dL), to reflect the latest research on the health effects of lead exposure. Studies show that even blood lead levels below 5 µg/dL can cause harm, including reduced intelligence quotient (IQ), attention deficits, and behavioral problems in children. No safe level of lead exposure has been identified, particularly for children.[14]

The 2022 Pennsylvania Childhood Lead Surveillance Annual Report (the most recent year published at the time of writing) showed that non-Hispanic Black or African American children had both the highest screening rates and the highest rates of confirmed elevated blood lead levels (defined as one venous blood lead test ≥3.5 µg/dL or 2 capillary blood lead tests ≥3.5 µg/dL drawn within 12 weeks of each other).[10] It is noteworthy that iron deficiency is also more prevalent in Black people than Caucasian people.[15]

Health care providers in Pennsylvania have a unique impetus to increase vigilance related to pica symptoms in their young patients, because their patients face higher risk than those in other geographic areas with younger housing stock. Pennsylvania's pediatricians can go above and beyond national standards by making it a matter of practice to ask pica screening questions at regular intervals, as well as whenever a child's blood lead result is above the reference value. Providers can also suggest additional blood level screenings when pica symptoms are observed. Addressing nutritional deficiencies in young children can help mitigate the effects of both pica and lead exposure, and additional awareness by providers of environmental exposures can help them to provide better patient care.

Blood lead level screening is currently recommended between 9 and 12 months and at 24 months of age.[10] All providers in Pennsylvania should be invested in increasing the childhood blood lead screening rate to the best of their abilities, and especially in at-risk populations. This can be accomplished by empowering caregivers through education on potential lead hazards and the importance of participation in lead screening tests. Clear and frequent communication with local health departments can help foster collaboration on lead poisoning prevention.

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Biography

Julia Kaya received a Masters in Public Health from the University of Vermont and works with childhood blood lead data at the Pennsylvania Department of Health.

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Trauma Sensitive Yoga: A Mindful Embodied Approach to Healing the Trauma of Sexual Abuse and Domestic Violence

Rachel Allen & Erika B. Brosig

Sexual abuse and domestic violence can have lasting impacts on the lives of survivors. Many survivors struggle with flashbacks, anxiety, depression, drug and alcohol abuse, difficulty trusting, and body-related issues, among other things. These interpersonal traumas impact how survivors relate to the outside world, but they also profoundly affect how they relate to their own bodies. The body, the site of the trauma, becomes unsafe, leading survivors to disconnect. Counseling can be incredibly beneficial in healing from sexual abuse and domestic violence. Still, for many survivors, some areas of impact cannot be reached through counseling alone.

In 2013, Rachel Allen RYT 200 (YogaSong) and Erika Brosig from Victim Services Inc. (VS - a sexual assault and domestic violence program) traveled to Omega Institute for the Yoga Service Council Conference featuring keynote speaker, Dr. Bessel van der Kolk, author of the pioneering book on trauma and healing, The Body Keeps the Score[1]. Moved by what they learned, Allen and Brosig, both survivors of interpersonal trauma themselves, returned home with enthusiasm and a commitment to bringing Trauma Sensitive Yoga (TSY) to their community. They connected with Rosemary Pawlowski, Executive Director of the BottleWorks Ethnic Arts Center, who had grant funding for a program that addressed trauma, but lacked a specific program to invest in. This newfound collaboration between The Bottle Works Ethnic Arts Center, VS, and YogaSong launched the Integrative Healing Group (IHG). This innovative ten-week group wove together the elements of a traditional support group, a TSY class, and self-expression through visual arts and music. Allen and Brosig developed the program with support from The Boston Area Rape

Crisis Center and Zabie Yamasaki, Founder of Transcending Sexual Trauma through Yoga, both who had long standing programs that positively impacted participants. More than a decade later, the program continues in our community, now offering ongoing TSY classes in person and via Zoom, all provided at no cost to the participants.

Trauma Sensitive Yoga

TSY teaches survivors a safe way to reconnect to their bodies and opens up a level of self-compassion that goes beyond what counseling alone can do. TSY is distinctly different from a typical yoga class. Language is invitational. Pace and flow are determined by the participant. Choice is offered in every form and the themes drawn from yoga philosophy are designed to help heal from trauma and sustain recovery. Pioneering research on the benefits of yoga for trauma survivors has been done across the country in places like Boston and California, and the results are promising[1]. An essential element in this research is TSY's ability to increase interoception, the ability to experience our visceral selves - for example, being able to feel our muscles contract or extend or sense our feet on the ground. Neuroscience shows there are specific brain pathways that light up when we are aware of moving muscles in the present moment. TSY's foundation in mindfulness brings present awareness to breath, body sensations, and movement. Research shows that TSY may help move the traumatized brain, which is stuck in the primitive limbic system, into the higher-level frontal cortex, where planning, strategizing, critical thinking, and connection reside[2].

Methods

The goal of the IHG and the TSY Program is to create a safe and healing environment through the practices of TSY and the healing arts, allowing survivors to reclaim their body in the healing process and, therefore, reclaim their life. The philosophy behind the programs draws from

research piloted by Bessel Van der Kolk and the Trauma Center at the Justice Resource Institute (now called the Center for Trauma and Embodiment at JRI), showing the efficacy of yoga in shifting the neurobiology of the traumatized brain[1]. The group and TSY classes bring together survivors who have felt isolated in their shame and guilt for most of their lives. TSY helps the participants become more comfortable in their bodies, often for the first time since the abuse occurred, and teaches them how to process their emotions in a healthy manner. Expression through music and art creates another pathway for the survivors to tell their stories, and the support group component gives them a sense of empowered community.

Initially designed for female-identifying individuals who are survivors of childhood sexual abuse, this project has since expanded to include survivors of domestic violence. Local foundations generously supported the program, funding three sessions of the IHG. Since then, ongoing TSY classes have been supported by Victims of Crime Act funding through the Pennsylvania Commission on Crime and Delinquency and provided at no cost to the participants.

The format of the IHG was based on the eight limbs of a trauma-informed yoga practice as outlined in Emotional Yoga: How the Body Can Heal the Mind[3]. The participants received a copy of the book, a journal, a folder, and index cards. Each week's 2.5-hour session included a check-in, sharing a quote about healing for participants to reflect on, and a discussion on the chapter for that week related to healing from trauma, led by Brosig, an experienced trauma therapist. This was followed by a brief break, and then the TSY practice led by Allen, a TSY-trained yoga teacher. Allen, also a Certified Music Practitioner and Sound Healer, guided expression through music throughout the sessions. During the first and last sessions, participants experienced expression through art, with a prompt to paint a representation of where they were in their healing journey at that time. The art created during these classes served as an outcome

measure for the group, along with comment cards completed at each session and pre-, mid-, and post-assessments of post-traumatic stress disorder (PTSD) symptoms. At the first, fifth, and final sessions of the group, participants were given the Adult Client Questionnaire (ACQ) developed by the Pennsylvania Coalition Against Rape (now the Pennsylvania Coalition to Advance Respect). Possible scores range from 25-125, with higher scores indicating more troublesome symptoms. At the start of the groups, the average ACQ score was 69. At the end of the ten-week sessions, scores dropped an average of 18 points, with one participant seeing a dramatic decrease of 53 points.

Ongoing TSY classes are still taught by Allen, and each class has a trained counselor from VS in attendance to support participants throughout the process. Participants are referred by agency staff or outside professionals. Each class introduces a yoga teaching related to healing, breathwork, gentle yoga asana, meditation, and incorporates music and sound healing. Participants can opt in or out of a brief check-out.

Case Presentation

Jessica is a 43-year-old survivor of sexual assault, domestic violence, and familial sex trafficking who battled substance use and an eating disorder for most of her life. She struggled with overwhelming feelings of sadness, loneliness, fear, self-doubt, guilt, and shame. Her trauma history led to anxiety, panic attacks, a very distorted view of her body, and longstanding intimacy issues.

Jessica learned about the IHG and TSY program through individual trauma therapy with Brosig. She reflected on the group, sharing that “Rachel showed me how to breathe and move and taught me that my body could hold positive energy, that when I released my breath, I could let go of all

the negatives that I was holding in my chest and my stomach for so very long. Yoga truly AMPLIFIED my ability to reconnect to my physical self. I learned how to give my body grace and to show it compassion for the first time. For over 15 years, I covered all the mirrors in my house so that I wouldn't have to see myself. Shortly after our yoga group ended, I was able to stand in front of the mirror again and see me, not the ugly feeling I felt inside for such a long time."

Jessica was working hard to heal the trauma from her childhood, but she was trapped in an intensely violent relationship. She felt stronger and more empowered as she connected with the group leaders and other survivors. That support, combined with the skills she was learning, created the inertia for change in her life. She recalls, "I will never forget driving after group one day, and I said to myself in my car, call Erika, you need out of this marriage. You can create safety for yourself and your children. Within the next 24 hours, I had a safety plan in place and asked him to leave. I started what felt like my whole life over again at 31 years old."

With a new life in front of her and a connection rebuilt with her body, Jessica found that she could shift her focus to her healing journey and forge a new path for herself and her children. She also discovered that being able to connect with herself gave her the ability to connect with her children in new, meaningful, and impactful ways. Over a decade later, that path has led Jessica to work at Victim Services Inc. Starting as an advocate, she has since grown with the agency and is now the Safe Housing Coordinator. Yoga remains a daily practice in her personal life and in her professional career as a certified TSY instructor for children 3-18 years old. She credits her experiences in therapy and TSY as the catalyst for change, and she now guides other survivors of domestic violence to safety, provides trauma therapy to survivors of all crimes, and chairs the county Human Trafficking Response Team.

Conclusions

The practice of TSY has taken root across the country and internationally, largely due to the publication of books like The Body Keeps the Score,[1] along with continued efforts in researching TSY's efficacy. Another key factor has been the commitment of individual practitioners to educating others. Allen and Brosig's successful collaboration brought TSY into the mainstream in their community and they were fortunate to have the opportunity to train other professionals in the model at the local, state, and national levels. Since that time, several VS staff members have been trained in providing TSY for children and adolescents, thus expanding the reach of the program to a younger demographic. This continued programming is a dream realized for both Allen and Brosig, who remain committed to serving survivors of interpersonal violence in all forms.

After more than a decade of providing TSY for survivors of sexual abuse and domestic violence, the authors are confident in its unique ability to reconnect survivors to their once alienated bodies and assist in creating a holistic healing process for trauma. This is particularly true when TSY is paired with other essential components of the healing process, such as building connection with other survivors, finding meaningful ways to reclaim their voices and share their stories, and empowering them to reclaim their bodies and their lives. The depth of transformation is best summarized in the words of one of the IHG participants, who shared the following: "For the first time I have found that I am not alone. That the events that changed my life no longer control me. I have a newfound freedom, which is full of peace, joy, love, and hope."

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Biographies

Rachel Allen is a Certified Music Practitioner, Sound Healer, Reiki Master, and Experienced Registered Yoga Teacher with over two decades of experience. She has served as a music practitioner in hospice care, provided Trauma Sensitive Yoga for over ten years, and facilitated expressive music for survivors of domestic violence, sexual assault, and individuals in recovery across various community-based settings. Her collaborations include organizations such as Victim Services Inc., the Pennsylvania Human Relations Commission, Torrance State Hospital, and Center for Population Health. Rachel is nationally affiliated with The Breathe Network as a rostered healing arts practitioner. She has over a decade of study at the intersection of yoga and social justice. Rachel holds many additional yoga certifications including as a Dynamic Gentle Yoga Teacher and an Accessible Yoga Teacher and Ambassador. She is also the author of the chapbook Blessings Beyond Bypass (SeedHouse Press, 2022), with her work featured in Northern Appalachia Review, Long Shot Books, and on the Christians Practicing Yoga Blog. Rachel facilitates yoga, healing music, and movement experiences at retreats and conferences, both in person and virtually. She also offers training on resilience building, compassion fatigue, trauma awareness, and mindfulness across the USA and internationally.

Erika Brosig is a Licensed Clinical Social Worker and the Chief Operating Officer at Victim Services, Inc. in Cambria and Somerset Counties in Pennsylvania. She's been with the agency since 2003 and in a leadership role since 2008. A survivor of sexual abuse, she has dedicated her career to creating healing spaces for other survivors through the use of evidence-based trauma therapy, along with cutting edge and holistic healing techniques. She is an expert in trauma treatment and trauma-informed care and is recognized as a Certified Trauma Treatment Specialist (CTTS) and an Eye Movement Desensitization and Reprocessing (EMDR) Certified Therapist, Approved Consultant, and Trainer. She also has expertise in grant writing and program development/implementation. In addition to her work at Victim Services, Inc., Erika is an adjunct professor for the University of Pittsburgh's Master's in Social Work program and an assistant trainer with the Trauma Institute & Child Trauma Institute. In 2020, Erika was selected as one of the 25-members of the Trauma Informed PA Think Tank out of Governor Wolf's Office of Advocacy and Reform, which developed a comprehensive plan to make Pennsylvania a Trauma-Informed State. In 2023, she published a chapter in the book Child Sexual Abuse: Practical Approaches to Prevention and Intervention entitled "Adult Survivors of Child Sexual Abuse: Living with the Effects of a Disrupted Childhood". Erika also serves as the Direct Services Committee Chair for the PA Association of Sexual Assault Centers and sits on the PA STOP Formula Grant Implementation Planning Committee. She has been recognized for her work by several national and state organizations, including being awarded the 2023 Ann Schumacher Rural Clinical Practice Award through the National Association for Rural Mental Health, the 2020 Visionary Voice Award through the National Sexual Violence Resource Center, and the 2019 Guardian of Victim's Rights Award through Marsy's Law Pennsylvania.

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Understanding Behavior as Communication When Supporting People with IDD

Craig Escudé, MD, FAAFP, FAADM, FAAIDD

Supporting people with intellectual and developmental disabilities (IDD) comes with the responsibility of understanding their unique ways of communicating. For many people with IDD, especially those who are unable to use words to communicate, behavior often becomes their primary form of expression. A sudden outburst, withdrawal, repetitive movement, or even a smile or gesture can carry important messages about their physical health, emotional state, environment, or unmet needs.

Rather than viewing challenging behaviors as problems to be fixed or controlled, it's essential to ask, "What is this person trying to tell me?" Behavior is communication, and often, it's the most accessible way for someone to express pain, frustration, fear, discomfort, confusion, or joy. Misinterpreting or ignoring these signals can lead to missed opportunities for support and connection.

As supporters, our role is to become skilled observers and compassionate interpreters. This means taking the time to understand each person's baseline behavior, recognizing changes that might indicate distress, and being attuned to triggers or environmental factors that influence behavior. Responding with empathy and curiosity, not judgment, builds trust and promotes safety and dignity.

Ultimately, when we listen closely to what people are telling us through their actions, we strengthen relationships and improve outcomes. In doing so, we honor each person's voice, whether spoken or unspoken, and affirm their right to be heard and understood.

The Purpose Behind Behavior

Every behavior has a purpose. Understanding that purpose helps us provide better support. Here are some common reasons a person might exhibit certain behaviors:

- **Seeking Access** – A person may be trying to get something they want, like a favorite item or activity.
- **Gaining Attention** – Sometimes, behaviors are used to connect with others. This isn't necessarily negative; it simply means the person has learned that a particular action gets them noticed.
- **Escaping a Situation** – If someone repeatedly "acts out" in a specific environment (such as when they are doing something they do not enjoy), they may have learned that this behavior results in being removed from the situation.
- **Avoiding Discomfort** – Some behaviors help a person avoid situations they find distressing.
- **Sensory or Internal Needs** – Certain behaviors may be responses to internal sensations, such as self-soothing or reacting to overstimulation.

Considering Medical or Physical Discomfort

A person's behavior is a sign of an underlying medical issue. Since some people cannot tell us when they are in pain or discomfort, their behavior can provide important clues. For example:

- A person who becomes aggressive at mealtimes might be experiencing nausea due to a medication side effect.
- Someone who screams when approaching the bathroom may anticipate pain with urination due to a bladder infection.

- A person who spits out food might be hungry but struggling with pain from a dental issue.

By paying close attention to patterns in behavior, we can identify potential health concerns and ensure those we support receive the care they need.

Connecting Behavior and Mental Health

Keep in mind that mental health conditions can result in challenging behaviors as well. “Acting out” may be a way of communicating emotional distress.

- Anxiety may appear as repetitive movements or pacing.
- Depression may appear as irritability or increased aggression, as well as withdrawal.
- Past trauma can lead to heightened fear responses, avoidance behaviors, or outbursts when triggered.
- Psychotic disorders may appear as confusion, paranoia, or agitation.

Recognizing Triggers

Observing when and where behaviors occur can help us understand what might be causing them. Consider these questions:

- Does the behavior only happen at certain times of the day?
- Does it only occur in specific environments or around certain people?
- Could the setting be a factor—such as loud noises or bright lights—cause distress?

By identifying triggers, we can adjust environments or approaches to better support the person’s comfort and well-being.

How Supporters Can Help

- **Recognize behavior as a form of communication** – Instead of viewing behaviors as "bad," ask, “What is this person trying to tell me?”
- **Look for changes in behavior** – A sudden increase in aggression, withdrawal, or self-injury may indicate discomfort.
- **Create a calm, predictable environment** – Structure and reassurance can help ease anxiety and emotional distress.
- **Advocate for appropriate mental health care** – People with IDD deserve access to proper psychiatric support, therapy, and medication if needed.
- **Encourage alternative communication methods** – Some individuals may express emotions through art, movement, or assistive technology rather than words.

Responding with Compassion

When supporting someone with intellectual disabilities, it’s essential to remember that behavior is often an attempt to communicate, not just something they "do." Instead of reacting negatively, we should ask ourselves: “What is this person trying to tell me?”

By approaching behaviors with curiosity, empathy, and patience, we can build stronger, more trusting relationships and help the individuals we support feel heard, valued, and respected.

Biography

Dr. Craig Escudé is a board-certified Fellow of the American Academy of Family Physicians, the American Academy of Developmental Medicine, The American Association on Intellectual and Developmental Disabilities, and President of IntellectAbility. He has more than 20 years of clinical experience providing medical care for people with IDD and complex medical and mental health conditions, serving as medical director of Hudspeth Regional Center in Mississippi for most of that time. While there, he founded DETECT, the Developmental Evaluation, Training, and Educational Consultative Team of Mississippi. He is the author of "Clinical Pearls in IDD Healthcare" and developer of the "Curriculum in IDD Healthcare," an eLearning course used to train clinicians on the fundamentals of healthcare for people with IDD, and the host of the IDD Health Matters Podcast.

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Positive Interactions Checklist to Evaluate Staff and Client Interactions

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Human connection is often acknowledged as an important part of maintaining a high quality of life.[1] Part of this human connection is fostered through caring, and positive interactions with family members, peers, and colleagues; however, people with developmental disabilities may have less access to meaningful relationships due to a variety of factors and barriers.[2] These barriers do not make relationships any less important and may mean that the importance of interactions with therapists and professional caregivers becomes a potential source to fill some of these relationship gaps.[3]

The relationship between a professional caregiver or therapist and the person receiving care may therefore have an important impact on the quality of support and life of people with intellectual and developmental disabilities.[4] It is important for health care professionals to foster positive human connections, because they may often represent a large degree of the social support that their patients receive.[1] People with disabilities often rely on help from their professional caregivers to assist them with their everyday tasks, including self-care skills, coping with challenging situations, communicating, and social interactions.[4] The degree of support that a person requires, as well as additional challenges such as behaviors of concern, may impact the frequency and quality of interaction with those providing support and care for a person. Therefore, putting a focus on positive interactions is warranted.[4]

The medical and nursing fields were some of the earliest to put an emphasis on the interactions and quality of care provided by nurses to their patients.[5] Efforts are ongoing within the health care system to enhance care quality and bring a more humanized approach to medical care; however, these efforts may inadvertently impact patient autonomy.[5] While research indicates that a strong nurse-patient relationship can shorten hospital stays and increase satisfaction with care, nurses report preferring passive or submissive patients, which may be indicative of a reduction in autonomy.[5] Despite this concern, inadequate nurse-patient relationships tend to compromise both the quality of care and autonomy, meaning that further investigation is needed to identify the best way to support both quality interactions and autonomy.[5]

Considerations of autonomy and quality of interactions are equally important within the community of therapists and professional care staff working with clients who have intellectual or developmental disabilities. Meaningful interactions have been defined as any type of interaction that is viewed as important or pleasing to clients or includes some type of functional or supportive action.[6] Positive staff to client interactions are imperative because not only do they reduce the likelihood that behaviors of concern will occur,[7] but they also allow staff valuable opportunities to get to know the specific needs of each client and enable them to respond in a person-centered and individualized way to those needs.[8] Social support has also been proposed to influence a person's degree of functioning, health perceptions, and overall quality of life.[9] Clients with disabilities who are treated with dignity and respect show improvements in well-being, making social interactions an imperative component of care.[10]

Simons et al. conducted a study to evaluate existing research on factors influencing the development of meaningful staff-client relationships. Findings indicated that negative attitudes

or interactions from staff resulted in an increase in challenging behavior from clients.[4] In a separate study, Vanono et al. examined the outcomes of staff participation in a workshop that focused on positive interactions. The researchers looked at the changes in the frequency of positive interactions between the staff and clients from baseline to after they completed the workshop. They used both the scores from the positive interaction checklist and the positive interaction checklist interview.[11] The results showed a small improvement in the positive interactions between staff and clients post-intervention.[11] The study also showed that the staff members all increased their knowledge and awareness of positive interactions and that their skills were maintained at a two month follow up.[11] Although this study did include a few questions to solicit the client perspective, the researchers noted a limitation, due to only providing clients with yes or no questions, thereby limiting the amount of information collected in this domain.[11] Screening measures that provided a broader opportunity for individuals receiving care to express their perspectives are needed.

Positive Interactions Rating Scale Development

The Positive Interaction Rating Scale (PIRS) was initially developed based on aspects of staff social interactions identified as important in existing literature, followed by expert and practitioner review in a series of nominal focus groups.[4 11] The domains selected as relevant based on the literature are as follows: support, verbal communication, and behavior. Each of those domains includes subdomains that break down both supportive and unsupportive staff qualities further. Additionally, PIRS includes interviews across all domains from both the supervisor and client perspectives. While a further examination of reliability and validity is needed, the PIRS presents a preliminary means of evaluating positive interactions to identify where further staff training may be needed.

Initial Evaluation and Validation of Content

Several peer-review measures were used to solicit expert opinions on the PIRS, including a series of focus groups and a final review to reach consensus on revisions using the Delphi Method. A nominal group technique is a structured small group discussion with experts on a specific topic used to reach a consensus on an idea.[12] During the group, the participants respond to questions provided by the moderator and give feedback on what has been presented to them during the meeting. Participants were asked to prioritize checklist components in order of most to least important. Additionally, they were asked to note any components they felt were redundant or unnecessary and to make recommendations on any components or domains they felt had been overlooked. Following ranking and discussion, participants voted to allow for a quantitative representation of proposed priorities and changes.

The experts included in the nominal group technique for the PIRS were experts in Applied Behavior Analysis (ABA), Organizational Behavior Management (OBM), supervision, and training. Before the meeting, the moderator emailed the participants the PIRS checklist to allow time to review the domains, subdomains, and questions. The focus groups began with a PowerPoint presentation providing an overview of the nominal group technique process and the PIRS. Participants were then provided with four questions: What domains are most important?;, aAre any domains missed; sShould any domains or subdomains be excluded?; and Is there anything else you would recommend adding or removing from the checklist? Once all four questions were answered, participants were allowed to discuss the responses and then asked to rank the responses in order of importance. The moderator collected the ranked responses and revised the checklist accordingly.

Following development and initial review during the focus group process, the Delphi Method was used to conduct a series of program reviews by a group of experts that included Board Certified Behavior Analysts (BCBA), who were also experts in OBM, ABA, supervision, and staff training. Revisions from these experts were included in the final draft of the program. Three rounds of revisions were made based on expert feedback until all three experts were satisfied with the checklist.

Domains of the PIRS

As mentioned, the domains included in the PIRS are support, verbal communication, and behavior. Questions are included across domains to evaluate supportive and unsupportive qualities of care exhibited by staff members. The initial rating scale is meant to observe staff members interacting with clients; however, this rating scale is followed by a second scale evaluating client perceptions across the same domains.

Supportive Qualities

Support

Meaningful interactions reflect a balance between client's needs and caregiver's support.[13] Clients with developmental disabilities require support to complete everyday tasks, to help with communication, challenging behavior, and coping.[10] Supportive qualities included in the PIRS were as follows: Presentness/proximity, training/assistance, choice/self-advocacy.

Presentness/Proximity. This domain aims to capture the extent to which a staff member remains present and maintains proximity to a person when appropriate, while respecting personal space. This is important as it ensures that clients feel they have access to a person if they need

assistance.[14] Staff engagement can also support the development of meaningful relationships for people who may have fewer than average opportunities to form these relationships.

Training/Assistance. Staff members also demonstrate support by using teaching methods appropriate for the learner's support needs with encouragement, while a person develops the skills to complete tasks confidently and independently.[15] Professional caregivers and therapists often take a significant role in supporting the development of new skills for those they care for.[16] Providing too much or too little prompting during a teaching procedure can cause frustration, prompt dependence, or failure to acquire the skill.[17] Providing an appropriate level of prompting is important to support independence, and both prompting and encouragement play a role in ensuring the teaching process is not stressful or aversive.[17]

Choice /Self-advocacy. Empowering clients through choice and advocating for self-determination are pivotal in fostering independence while maintaining health and safety.[18] When clients are involved in the decision-making process, it not only promotes autonomy, but also contributes to a sense of agency and self-esteem. Providing opportunities for choices can be integrated into daily routines, including a variety of decisions, such as selecting outings and leisure activities, providing input on meal planning, identifying preferred forms of positive reinforcement, and setting personal goals. By creating a supportive environment where clients are encouraged to express their preferences and feel respected in doing so, staff can enhance the overall quality of life of those they support.

Verbal Communication

Communication is a dynamic process that includes interacting and engaging with others.[19] Verbal communication includes vocally expressed words, the accompanying sounds, and the tone of voice used to convey meaning. Communication skills are critical in many aspects of life, influencing interpersonal relationships and giving context to the intent of spoken words. Supportive communication is often characterized by attributes such as enthusiasm, verbal warmth, and humor. [22 28 20 3 22]

Verbal Warmth. Verbal warmth is demonstrated when a staff member uses kind, positive, or encouraging words to address their clients.[20] Studies indicate that positive verbal interactions are correlated with enhanced well-being and life satisfaction among clients. [21]

Humor. Humor can be understood as communicative behavior that results in laughter. [22] Humor in interactions between health care providers and clients is a valuable and often underutilized resource.[23] Humorous interaction has been shown to have a positive impact on both health care providers and their clients and can help reduce anxiety, depression, and embarrassment.[23]

Behavior

Interpersonal staff behavior is one of the most influential factors associated with challenging behaviors in clients with disabilities. [24] Key behaviors from staff that can shape client development include non-verbal warmth, cultural sensitivity, patience, flexibility, trust-building, respecting client privacy, and positive behavior management. Conversely, staff behaviors can be counterproductive and sometimes evoke or encourage challenging behaviors. [24] Improving the quality of the social interactions between staff and clients can substantially improve clients' life experiences. [11]

Non-verbal Warmth. Expressions of non-verbal warmth such as appropriate physical touch, smiles, and positive body language are a useful means of demonstrating support and care, especially for clients with communication difficulties. Gestures such as high-fives and touches on the shoulder, silly facial expressions, and smiles, contribute to a positive atmosphere.[20] Body-language cues that indicate attentiveness to a client include facing the client, making eye contact, and active listening. [25]

Cultural Sensitivity. When a staff member is sensitive to cultural differences, it demonstrates respect for different backgrounds, traditions, norms, beliefs, and values that may be important to the people they support. When staff demonstrate understanding and acceptance of various perspectives, it fosters stronger, more equitable relationships.[26] Observing cultural sensitivity ensures that all clients are treated equitably, regardless of their background or diagnosis.

Patience and Flexibility. People with intellectual and developmental disabilities may exhibit a variety of communication, learning, behavioral, and physical challenges[27] that necessitate tailored support, and result in the need for assistance completing tasks of daily living. It is often helpful for professional caretakers to embody patience, as demonstrated by providing extra time and accommodations in response to client challenges without displaying frustration.[28] Additionally, flexibility in caregiver approaches allows for adjustments tailored to an individual client's needs. Caregivers open to trying new approaches if current procedures are not working or are causing distress, can help reduce the likelihood that daily tasks become stressful or aversive.[29]

Trust and Providing Privacy. Trust is an important aspect of any interpersonal relationship, and the staff to client relationship is no different. Reliability and consistency across interactions

can help build a trusting relationship between professional caregivers and their clients.[30] Trust extends to ensuring privacy, with Health Insurance Portability and Accountability Act (HIPAA) laws guiding the protection of personal information. [31] In addition to the privacy of personal information, people receiving care also benefit from personal privacy. This can include providing a person with personal space when safety is not at risk, especially when a person is using the bathroom, bathing, changing, or when a client requests to be alone.[32]

Positive Behavior Management. Positive behavior management involves using reinforcement strategies to support clients in developing adaptive and functional skills.[33] Core principles of this approach include upholding client respect, providing social validation, maintaining dignity, embracing person-centered planning, and fostering self-determination.[33] These principles align with the Behavioral Analysis Certification Board (BACB) ethical code, which emphasizes reinforcement, and encourages consistency in maintaining the least restrictive environment possible. Using positive behavior management strategies can reduce the likelihood of aversive control, improving quality of life.[33]

Unsupportive Qualities

Support

The current body of literature indicates that not all staff qualities and behaviors support positive outcomes. Detrimental staff behaviors can include impeding independence by providing unnecessary or unwelcome support or being neglectful or non-responsive to clients.[34 35 36 37 38]

Preventing Independence. Genuine support involves enabling clients to do as much as they can independently, thus promoting autonomy and reducing overbearing supervision.[34] Professional care providers should support the development of adaptive skills that promote self-sufficiency,

rather than completing tasks on behalf of clients without providing guidance or training.[35] Additionally, ignoring a person's attempts to self-advocate denies them their right to autonomy. It is widely accepted that every person has the right to make informed decisions about their health care, and health care professionals should not impose their own beliefs or decisions upon their patients.[36] Although some issues may arise based on the client's capacity to make decisions on serious matters, efforts should be made to provide opportunities for informed choices whenever safe and healthy.

Neglect. Neglectful behavior includes failing to engage with clients either verbally or non-verbally, particularly when doing so includes failing to address immediate needs.[39] [37] Neglect can involve being non-responsive to a person's requests or questions and ignoring the person.[39] Trained professional care providers should be able to recognize the difference between neglectful behavior and recognizing a client's need for solitude or privacy, and to find the balance between respecting personal time and meeting care needs.

Verbal Communication

Effective and respectful communication by staff is central to maintaining a positive and supportive environment. The use of disrespectful language undermines client dignity and should be avoided.[40] [29]

Disrespectful Language. Using disrespectful language can include behaviors like being rude or discourteous by using offensive or dismissive language to address a person. It can also include using language that trivializes a person's concerns or reduces their identity to their diagnosis. These types of interactions often belittle and "bother" clients, rather than bolstering their self-worth. Well-intended discussions, such as discussing a client's behavior with a supervisor, may

also be perceived as disrespectful by the person being discussed, so it is imperative to maintain privacy and respect in such conversations.[41]

Behavior

Unsupportive behavioral qualities in staff members can negatively impact client well-being. Such behaviors include using coercive control, being non-inclusive, and acting disrespectfully towards clients and their privacy.[42] [43] [44]

Coercive Control. Coercive control includes any verbal or non-verbal behavior that uses punishment, threats of punishment, humiliation, intimidation, or other forms of verbal or physical abuse, used to control a person's behavior.[43] Given the degree of harm that can occur because of coercive control, this type of behavior should be avoided at all costs.

Non-inclusive. Being non-inclusive may involve unnecessarily denying clients access to events or activities. This excludes instances where the activity may endanger the client's health and safety, and there is no reasonable accommodation.[44] Staff should actively work to include clients and provide them with a choice of reasonable and appropriate activities, and make accommodations as needed to facilitate client involvement.

Disrespectful. Disrespectful behavior may include avoiding eye contact during interactions and conversations or making negative facial expressions, such as eye-rolling or frowning at a client.[42] When a staff member disrespects their client's privacy, they are crossing a person's boundaries and violating their trust. Disrespectful comments can also negatively affect a client's mental health and model negative behaviors that clients may imitate.

Clients' Behavior

There are often many challenging aspects to working with clients within the intellectual and/or developmental disability (IDD) population. One such challenge includes behaviors of concern exhibited by the client.[4] Clients' challenging behaviors can impact staff morale, leading to decreased social interaction and quality of care.[4] Client behavior may also contribute to high rates of staff turnover and burnout. An increase in staff turnover rates may have a negative effect on clients with Autism Spectrum Disorder .[45] Research has linked staff turnover rates to job satisfaction and training adequacy, suggesting that improved training may help improve staff retention. Additionally, research indicates that staff burnout is often correlated with attitudes toward clients with disabilities, pointing to a need for better training on potential challenges.[46]

For clients with IDD experiencing developmental delays, communication barriers can hinder social engagement and negatively affect quality of life.[47] Diverse communication methods such as sign language, picture exchange cards, and augmentative and alternative communication devices, in addition to limited language, can make it difficult to have meaningful conversations. Studies have shown that better training and improved environmental support are needed to continue to enhance relationships for people with IDD.[48]

Discussion

The domains support, communication, and behavior were chosen as the basis of the PIRS because of the important role they play in social interactions.[25] [11] Providing positive support can lead to healthier relationships between staff and clients. Whether staff members engage in supportive or unsupportive communication also impacts the responses and mood of their clients.[36] Staff behavior has been shown to be one of the most influential factors resulting in

success or failure when working with clients with IDD.[49] The PIRS subdomains and questions are designed to help capture and measure the quality of care provided by staff members and indicate areas where a staff member may need more training. Since the PIRS provides both the supervisor's and clients' perspectives on staff members' supportive and unsupportive qualities, the checklist offers a diverse perspective and ensures that all relevant stakeholders can provide input to the greatest degree possible.

Previous research has shown the importance of having positive staff and client interactions for both the quality of life for clients and the job satisfaction for staff members.[9 13 50] The relationship between a professional caregiver or therapist and the person receiving care may, therefore, have an important impact on the quality of support and life of people with intellectual and developmental disabilities.[51] Positive staff engagement, providing choices, positive verbal interactions, patience, and flexibility are just some of the supportive qualities found in other studies that, when used in interactions with clients with IDD, have shown improvements.[28 51 14 18] Staff members play a role in providing those they support with a more meaningful life, and daily interactions can have a significant impact on health and well-being. The PIRS, while preliminary, presents a means of assessing professional caregiver to client behavior and relationships, and is unique in that it includes client perspectives and input.

Future Research

While this checklist has undergone extensive evaluation by experts in the field, much additional work is needed to evaluate the reliability and validity of the checklist. An evaluation of the PIRS during real-world applications would contribute to evaluating the feasibility and perceptions of professional caregivers, clients with IDD, and supervisors. The checklist would also benefit from

ensuring that checklist responses remain consistent over time, and that independent raters demonstrate consistency when evaluating instances of staff behavior. Assessing the validity and reliability of the tool will help ensure the integrity, quality, and overall usefulness of the tool as an assessment measure capable of informing potential interventions.[3]

Author Note

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