

# POSITIVE APPROACHES JOURNAL

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## **The Intersection of Mental and Physical Health Impacting our Communities: Part 1**

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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 4.

**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.

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## Introduction

Everyone has a right to an everyday life that includes being as healthy as possible both mentally and physically. Participating in and having the best possible everyday life can be challenging for individuals with an intellectual disability and/or autism (ID/A), especially if they have both physical and mental health needs. These individuals may need specific support and treatment to ensure they can achieve their best possible everyday life. In collaboration with the Information Sharing and Advisory Committee (ISAC), a list of 12 recommendations were developed to support individuals with ID/A in achieving their best possible everyday life. Recommendation five (5) is to promote health, wellness, and safety. Recommendation six (6) is to support people with complex needs. Representing resources from both the Office of Developmental Programs (ODP) and the Office of Mental Health and Substance Abuse Services (OMHSAS), the next two issues of the Positive Approaches Journal are devoted to the discussion of topics related to challenges around maintaining and supporting both physical and mental health and to provide information on resources.

In this first issue we will discuss the shortage of both primary health and mental health care professionals. We will also discuss the five primary health conditions that can significantly elevate the risk of severe illness and death in individuals with ID/A, supporting nutritional needs of individuals with autism, utilizing a public health approach to address wellness for individuals who have encountered trauma, and supporting individuals and their families who have survived suicide.

Rhonda Gengler, BSN, RN  
Chief Nursing Officer

## Data Discoveries

### Health Professional Shortage Areas in Pennsylvania

The need for health care services in the United States has increased significantly in recent years as the population ages and grows, and there is some evidence suggesting that this need will soon outpace provider availability, exacerbating disparities in access to care. The National Center for Health Workforce Analysis projects that the United States will experience a total shortage of 187,130 full-time equivalent physicians in 2037, and 31 out of 35 specialties are expected to encounter shortages.<sup>1</sup> Family Medicine is projected to experience a significant shortage, meeting only 73% of the projected need for services; similarly, General Internal Medicine is projected to meet 76% of that need. This could mean that about a quarter of those who need primary health care services will not be able to access them.

The United States is also facing a mental health crisis with increasing unmet behavioral health needs across people of all ages. Behavioral health services can be difficult to access due to high costs, coverage gaps, and provider shortages.<sup>2</sup> Currently, over one-third of the U.S. population lives in a Mental HealthCare Health Professional Shortage Area (HPSA), and substantial behavioral health worker shortages are projected in the future.<sup>2</sup> Rural counties are often at greater risk for provider shortages compared to metro areas, further exacerbating unmet needs and access to services.<sup>1,2</sup>

People with intellectual and developmental disabilities (IDD), including those with autism and intellectual disabilities, often have multiple physical health and mental health needs,<sup>3</sup> and experience higher rates of co-occurring mental health conditions compared to their peers without IDD.<sup>4</sup> Autistic people are more likely to have unmet health care needs, experience challenges

accessing treatment or counseling, and encounter higher health care costs compared to non-autistic people.<sup>3</sup> Living in an HPSA may further increase risk for poor health and mental health outcomes among people with IDD, underscoring the importance of examining the percentage of this population who may be at risk for limitations in access to health care services due to a shortage of providers. Autistic Pennsylvanians of all ages and their families have reported difficulties finding needed services.<sup>5</sup> Pennsylvania Autism Needs Assessment (PANA) data suggest that the most common barrier to accessing care is a lack of providers, and parents have reported no or few providers for specific needed services.<sup>5</sup> This lack of provider access was reported to be worse in rural areas and for adult services.<sup>6</sup>

The dashboard below displays the percentage of Pennsylvanians with and without IDD who live in Health Professional Shortage Areas. The Health Resources and Service Administration (HRSA) defines HPSAs as geographic areas, populations, and/or facilities that have a shortage of primary, dental, and/or mental health care providers. The dashboard focuses on geographic HPSAs, which are areas in which the entire population experiences the shortage and reflects the percentage of Pennsylvania Medicaid enrollees whose zip codes fall into geographic HRSA-defined HPSAs. The data can be filtered by important demographic characteristics, including age group, insurance, race/ethnicity, and gender. To provide national context and relevant comparison data for Pennsylvania, dashboard users may also view the percentage of those living in HPSA in New York, North Carolina, and Ohio. These states were selected as useful points of comparison due to their similarities in population, population density, median income, unemployment rates, and or geographic proximity.

These data suggest that overall, a greater percentage of Medicaid enrollees in Pennsylvania live in a mental health professional shortage area compared to a primary care professional shortage



area. This pattern is observed across most of the other states included in this dashboard. Across all age groups, a higher percentage of Pennsylvanians with IDD live in a mental health professional shortage area compared to people without IDD. Notably, however, we observe the greatest disparity between those with and without IDD in the 18–21-year-old age range, with 14% of those with IDD living in a mental health professional shortage area compared to 11% of those without IDD.

The proportion of Medicaid enrollees with IDD who live in either a primary care or mental health professional shortage area also increases with age: 12% of Medicaid enrollees with IDD aged 1-17 live in HPSAs compared to 16% of those with IDD aged 40-64. Disparities are also observed across race/ethnicity and disability status: in Pennsylvania, 3.6% of Black people with IDD live in HPSAs compared to 3.1% of Black people without IDD. These differences are similar across the other states included in this dashboard.

These findings highlight the importance of increasing access to primary care and mental health professionals for people with disabilities. This includes not only increasing the number of providers available in each area, but also improving knowledge and awareness of IDD among those providers to best support people in need of these services. Provider incentives, including those to encourage telehealth offerings, may support increased access, especially for people who live in rural areas. As the need for both physical health and mental health services persists, it is critical to continue monitoring how these shortages impact people with IDD in Pennsylvania.

[\*\*\*Link to Data Discoveries Dashboard\*\*\*](#)

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## **Applying Public Health Principles to Health Psychology**

**Kate Fox, DrPH (c), MPH**

### **Introduction**

Health psychology refers to a field of study that examines how psychological factors influence health and illness, including thoughts, emotions, and actions<sup>1</sup>. Framing health and wellness as an individual responsibility overlooks the broader systemic and social drivers that shape health and mental health outcomes. A public health approach to psychological and mental health is desperately needed. Public health principles emphasize population-level interventions and structural changes, offering valuable insights to improve health and wellness. This article explores how systemic factors influence mental health and discusses public health policy solutions aimed at addressing systemic trauma to promote population wellness.

### **Systemic and Social Drivers of Mental Health**

In the latter half of the twentieth century, mental health as a field has made significant advances in scientific understanding of mental disorders, focusing primarily on disease pathways such as neurotransmitters and hormones (e.g. serotonin, dopamine). The advent of pharmacological options to treat mental illness such as depression, anxiety, bipolar disorder, and schizophrenia marked a significant transition in the field to psychopharmacology, neurological approaches, and the pathologization of mental illness. As recently as 1977, 64% of psychiatric visits were exclusively for psychotherapy without an accompanying prescribed medication; in 2002, this was true for less than 10% of psychiatric visits<sup>2</sup>.

Despite these scientific advancements, the population's mental health has continued to decline.

The number of people receiving mental health treatment has increased by 15 million people since 2002<sup>3</sup>. One in eight U.S. adults is currently taking an antidepressant<sup>4</sup>. The COVID-19 pandemic ignited national conversation about mental health, with the Surgeon General issuing a warning around youth mental health and workplace mental health in 2021 and 2022 respectively<sup>5,6</sup>.

Despite significant shifts in the scientific knowledge base underpinning the mental health field, America's mental health crisis has only worsened. Almost a third of United States (U.S.) adults report symptoms of depression or anxiety, which is three times higher than those reporting symptoms in 2019<sup>7</sup>. In 2022, only 31% of U.S. adults considered their mental health "excellent," a decrease of 43% from the same report in 2002<sup>8</sup>. In 2022, the Centers for Disease Control and Prevention (CDC) recorded the highest rate of suicides in the nation's history, an increase of over 30% since 2000<sup>9</sup>. While efforts to increase access to evidence-based treatments, therapeutic interventions, and tech-based solutions have advanced, the field is falling short in addressing the mental health needs of the population.

This is where public health comes in. To date, approaches to solving the mental health crisis have been targeted primarily at the individual level, adhering to the traditional medical model of diagnosing and treating illness. A public health approach focuses on preventing disease among a whole population by addressing risk factors at the community level.

Consider the single mother I interviewed living in Delaware County, PA. She has a full-time job, a part-time job, and is raising a daughter with significant mental health challenges. Despite recognizing the importance of mental health and self-care, she has neither the time nor the resources to engage in wellness activities such as therapy, exercise, or even regular medical

check-ups. The expectation that she should just “manage stress better” or “take a bubble bath” disregards the systemic factors that create and sustain these conditions. Instead of placing the burden of wellness solely on the individual, policies should focus on systemic reforms that alleviate these pressures.

### **Lack of Preventative Care in Mental Health**

Public health has made significant advancements in the physical health care system that have yet to be made in mental health care. In primary care, individuals can seek treatment for minor ailments like colds or infections without requiring a formal diagnosis. Preventative measures such as vaccinations, routine screenings, and general wellness check-ups serve as the first line of defense against more severe illnesses. These proactive interventions reduce the burden on emergency services and improve long-term health outcomes.

Mental health care, however, lacks the equivalent first line of defense. Access to mental health care typically requires a formal diagnosis, insurance approvals, and other barriers that make early intervention difficult. Instead of a system designed to provide proactive support, mental health services are typically responsive – only available once symptoms become severe enough to warrant intervention. This gap in early access causes worsened health outcomes and places unnecessary strain on an already overburdened crisis system.

By applying a public health approach to mental health care, preventative care could be expanded, mirroring successful strategies in primary care. Community-based mental wellness programs, workplace mental health screenings, and school-based access to counseling could build a preventive care system to address mental health challenges before they escalate. Just as vaccines help prevent illness in physical health, mental health interventions can serve as population-level protective factors against more severe mental health conditions.

## Policy Solutions for Systemic Change

To move beyond the traditional individual-centered approach to mental health, policymakers and public health professionals must implement strategic, systemic interventions that address the root causes of poor mental health. Key strategies include:

- **Economic policies to reduce financial stress:** Policies such as a living wage, paid family leave, and guaranteed minimum income can help reduce the financial stress on working families, allowing individuals the stability needed to prioritize mental health and physical health.
- **Community-based mental health services:** Mental health services must be re-imagined as services that support mental well-being, not just clinical services that respond to mental illness. Expanding access to community-centered mental health care could include programs such as youth mentoring and recreational programming, school-based counseling, and peer support initiatives that increase accessibility to mental well-being supports.
- **Ensure appropriate access to community-based mental health services:** Every individual in need of mental wellness support does not meet the clinical diagnostic criteria necessary to receive services. Policymakers can ensure that the definition of medical necessity is interpreted broadly to authorize mental well-being services and payments for a broad range of individuals.
- **Increase availability of dyadic care models:** Mental health and well-being is driven by a family's health. Parents and caregivers need support to reduce stress and be the best caregivers they can be. Dyadic care refers to care that is provided to children and their

families together. Increasing access to dyadic care models ensures that families can heal together.

For a detailed analysis of policy recommendations for Pennsylvania's Medicaid HealthChoices program, please see the Children First report [\*Optimizing Medicaid to Improve Child and Youth Mental Health in Pennsylvania\*](#).

## **Conclusion**

Public health principles offer a critical framework for addressing mental health and well-being at a systemic level. Rather than placing the responsibility for well-being solely on an individual, a population-level approach recognizes the role of social and systemic drivers in shaping health outcomes. By implementing policies that address economic stress, expand community-based solutions, and integrate trauma-informed practices, we can create healthy environments that support long-term wellness for all. Health psychology must evolve beyond personal responsibility narratives and embrace systemic change as a necessary foundation to promote population health.

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## Biography

**Kate Fox** is a daughter, a mother, a partner, a sister, and an advocate for social change in mental health systems. In her work at Children First, Kate leads efforts to improve school-based mental health, increase access to services, and promote healing-centered approaches to children's mental health. Prior to Children First, Kate spent ten years working in public service at Philadelphia's Department of Behavioral Health and Intellectual disAbility Services (DBHIDS). Kate is also a doctoral candidate in health management and policy at Drexel University's Dornsife School of Public Health, where she is working on a dissertation on establishing mental health justice principles in practice and in policy. Outside of work, Kate likes to focus on raising the next generation of socially conscious leaders by spending time with her young daughter.

## Contact Information

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## Cooking with Confidence for Autistic Individuals

Mi-Yeet Wong

What if we reimagine our approach to whole health? Instead of addressing isolated aspects of a person's life, we could take a more holistic view—one that considers the interconnected factors shaping their well-being. Take cooking, for example. Rather than simply teaching people how to prepare meals, we could explore their first experiences with cooking, their access to ingredients, the foods they enjoy, and how often they share meals with others. From an educational standpoint, how can we equip individuals to assess a food's nutritional value in a way that aligns with their unique health needs? And from a systems perspective, how can we leverage existing resources to create sustainable opportunities that foster long-term well-being? These are all questions we have explored in our community-based program *Cooking with Confidence for Autistic Individuals*. This article will share insights from the program, highlight existing initiatives and resources, and discuss opportunities for future development.

### *Philosophy*

*Cooking with Confidence for Autistic Individuals* is grounded in multiple conceptual frameworks and philosophies that shape its purpose, reach, and implementation. These approaches include *Food is Medicine*,<sup>2</sup> the belief that community is intervention, the *Living an Everyday Life* framework,<sup>1</sup> and a commitment to program implementation through a health equity lens.<sup>3</sup>

- **Food is Medicine** is defined as the “provision of healthy food to prevent, manage, or treat specific clinical conditions in a way that is integrated with the health sector”.<sup>2</sup> This concept acknowledges that food is essential not only for survival but for overall well-being. What we eat directly impacts how we feel, and food carries deep cultural

significance. *Food is Medicine* encourages us to recognize and harness the power of nutrition interventions and policies to improve health outcomes.

- The belief that **community is intervention** emphasizes the organic support and learning that emerges when individuals engage in meaningful spaces with their peers. It underscores the profound impact of loneliness<sup>4</sup>, particularly for autistic individuals—over half of autistic teens experience significant difficulties in forming and maintaining friendships, while more than one-third face barriers to accessing or being included in spaces outside their homes.<sup>5</sup> This approach highlights the importance of fostering inclusive, supportive communities as a vital aspect of well-being.
- *Envisioning an Everyday Life*<sup>1</sup> emphasizes the power of high expectations—the belief that we *can* broaden our vision and take meaningful steps toward creating the life we want to live. It challenges us to consider whether our actions truly support individuals in making choices that align with their vision of a fulfilling everyday life.
- Implementation through a **health equity lens**<sup>3</sup> challenges us to assess whether our programs and supports are reaching those who need them most—and to identify and address any gaps in access or impact.

With these guiding principles in mind, *Cooking with Confidence for Autistic Individuals* provides hands-on cooking experiences that bridge physical health with mental well-being, fostering skills, connection, and empowerment.

## Program Background

### *Leveraging Partnerships*

The partnership between the Philadelphia Autism Project and the Free Library of Philadelphia began with the development of Sensory Storytimes—special library sessions that provided extended hours exclusively for families of children on the spectrum, creating an inclusive and judgment-free storytelling experience. Building on this collaboration, the Philadelphia Autism Project recognized an opportunity to expand inclusion beyond storytelling and into the kitchen. When they learned about the mission and programming of the Free Library’s Culinary Literacy Center (CLC), <sup>6</sup> they saw cooking as a powerful tool for engagement and learning. Founded in 2014, the CLC promotes literacy through cooking, integrating math, reading, and science into hands-on learning experiences. By exploring new foods, tools, and techniques, participants of all ages gain both culinary and educational skills. Committed to accessibility and inclusion, the CLC offers a range of programs, including *Cooking with Confidence Program for Autistic Individuals*, designed for individuals on the spectrum.

Planning for the *Cooking with Confidence Program for Autistic Individuals* began in 2017 with support from a university seed grant aimed at driving innovative projects. Following this initial funding, the Philadelphia Autism Project contributed funds, complemented by a matching grant from the Free Library of Philadelphia Foundation. By leveraging existing city-funded resources and forging innovative partnerships with an interdisciplinary team—including the CLC, AJ Drexel Autism Institute (an autism research center operating within a university), Drexel Food Lab (connected with a university College of Nursing and Health Professions), and National Institutes of Health Clinical Center (a national center focused on diseases, illnesses, and related solutions) - the program has expanded to incorporate nutrition analysis, an evaluation

component, and additional recipes. When exploring funding opportunities, tapping into local city-funded or university resources can be a powerful catalyst for launching new programs.

### ***Program Components***

The *Cooking with Confidence Program for Autistic Individuals* is a community-based educational program where autistic individuals practice independent living skills, health promotion activities, and participate in social and community engagement through hands-on cooking classes. As the program is implemented in an urban city where there are high poverty rates<sup>7</sup> and food insecurity,<sup>8-9</sup> the development of this program considered accessibility and affordability. Recipes were chosen based on affordability and in alignment with SNAP benefits.<sup>10</sup> The program was offered at no cost to participants, and if transportation challenges arose, program coordinators offered additional funding to secure transportation. Accessibility was considered throughout the program development and implementation - from recipe selection and the strategic breakdown of tasks to the registration process and communication on accommodations needed.<sup>11</sup>

Through hands-on classes, participants practice essential skills such as reading recipes, practicing basic cooking techniques, and maintaining kitchen safety. They prepare a plant-based meal and gather around a communal table, where they explore and discuss unfamiliar foods in a supportive social setting. Participants bring a diverse range of experiences, enriching the learning environment. Beyond nutrition and cooking, they engage in conversations about stepping outside their comfort zones, encouraged by their peers. While these moments may seem small, they hold significant value. For individuals who thrive on consistency and routine—whether in their schedules, environments, or diets—trying something new can expand their own perceptions, as well as those of their support network, about what is possible. Program staff can pair this

opportunity with connecting participants to resources, such as supporting participants in applying for a Free Library card, the use of travel training to commute to the library or sharing autism-related resources.

### **Resources, Research and Policy**

While the *Cooking with Confidence Program for Autistic Individuals* serves as a promising model for future expansion, many other valuable culinary programs and resources also deserve recognition. Below is a selection of resources, though it is not an exhaustive list.

- [\*\*The Gus Schumacher Nutrition Incentive Program – National Training, Technical Assistance, Evaluation, and Information Centers Program \(GusNIP-NTAE\):\*\*](#)  
Provides funding to bring stakeholders together and offer training and support, helping them explore strategies to improve the health and nutrition of participating households.
- [\*\*ASD Nutrition Study:\*\*](#) A randomized controlled trial funded by the National Institute of Health (NIH) to evaluate the feasibility and efficacy of a nutrition education intervention for children on the spectrum and their parents.
- [\*\*Food is Medicine: A State Medicaid Policy Toolkit:\*\*](#) Provides a roadmap that helps state officials identify the most effective and practical approaches to addressing patient nutrition needs within their state's Medicaid and Children's Health Insurance Program (CHIP) programs.

### **Future Direction**

There are numerous opportunities to expand the *Cooking with Confidence Program for Autistic Individuals*. Potential next steps include developing a curriculum based on key learnings to support program replication in new settings, integrating a nutritionist-led lesson plan to educate participants during sessions, and further exploring the connection between food selectivity and

autism to inform recipe selection. By building on these foundations, the program can continue to empower individuals, foster inclusion, and enhance well-being across diverse communities.

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## **Biography**

**Mi-Yeet Wong** uses her prior experience as a Case Manager for adults with developmental differences to contribute to her current work in supporting individuals, their family members, and the community through program development and resource navigation. She connects with autistic individuals and their families through the statewide resource center “warmline,” develops resources informed by community feedback, and embeds community-informed infrastructure across projects.

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## The Fatal Five and the Importance of Monitoring

Jenifer Baker RN, CDDN, CDP

The "Fatal Five" refers to the five primary conditions that significantly elevate the risk of mortality in individuals with intellectual and developmental disabilities (IDD). These conditions include aspiration, seizures, constipation, dehydration, and infection/sepsis. Notably, many of these conditions are often preventable. However, they may frequently go unrecognized, be misdiagnosed, or be mistaken for behavioral expressions. By promoting education and increasing awareness within family members, support persons, and the individuals themselves, regarding the significance of monitoring, documenting, and reporting these conditions to health care professionals, it is possible to help to reduce the risk of fatalities associated with these conditions.

**Aspiration** refers to the process in which foreign objects such as food, liquids, medications, or even a person's own secretions, are inhaled into the lungs. It can lead to respiratory infections that can be serious and life-threatening such as pneumonia. There can be obvious signs that someone has aspirated, but there can also be subtle signs. It can be especially difficult if the person is unable to communicate that they have had difficulty swallowing or have had choking episodes. Signs that may indicate a person has aspirated can include:

- Coughing or excessive drooling with eating or drinking
- Wet sounding breath when breathing in
- Wheezing
- Frequent throat clearing

- Unexplained fever
- Inability to breathe, difficulty breathing or shortness of breath
- Inability to speak, look of panic
- Pale or blue in color
- Respiratory infections

Individuals with IDD may experience an elevated risk of aspiration due to conditions such as seizure disorders, cerebral palsy, and dysphagia. Additionally, certain medications can further increase this risk by impairing alertness. Particularly, anticholinergics such as diphenhydramine (Benadryl), commonly used to relieve allergy symptoms; oxybutynin (Ditropan) and tolterodine (Detrol), both used to treat symptoms of overactive bladder; and benztropine (Cogentin), prescribed to treat Parkinson's disease and medication-induced movement disorders. Certain psychotropics and muscle relaxants can also contribute to decreased awareness. Should the individual have a meal plan in place which modifies the consistency of foods and liquids, it is imperative that this plan is strictly followed. Vigilant monitoring for signs of aspiration, along with ensuring appropriate seating and positioning during meals is essential. Should any indicators of aspiration or respiratory infections arise, it is crucial to consult a medical provider for prompt evaluation.

**Seizures** are abnormal electrical responses in the brain which may result in involuntary physical and behavioral changes. There are several different types of seizures. Some may be obvious, such as with a tonic-clonic (formerly known as grand mal) seizure, or the seizure may be so subtle that it goes unnoticed, such as with an absence seizure (staring seizures), certain focal

seizures (complex partial seizures), and even atonic seizures (drop seizures). The understanding that seizures will vary and look different for each person is important when monitoring for signs.

Below are signs that might be seen when a person has a seizure.

- Loss of consciousness or awareness
- Brief staring spells, subtle eye blinking
- Lip smacking, slight movements of the mouth
- Hand wringing
- Picking at clothes
- Sudden loss of muscle tone, leading to dropping to the ground
- Uncontrolled twitching or jerking of arms or legs
- Confusion, anxiety, or anger
- Hitting others
- Not listening or being able to follow directions
- Gaps in memory

For some individuals, these signs may be mistaken for unprovoked behavioral outbursts. This can lead to misdiagnosis. When the seizure does occur, note the time the active seizure started and stopped and what was observed before, during, and after. It is also helpful to ask the person if they can provide any insight into what they have experienced or felt before, during, or after the seizure. Documenting known seizure triggers can also be insightful when supporting and monitoring someone who has seizures. Always clear the area for the person who is having the seizure, keep them safe, and never place anything in their mouth. Call 911 if it is their first seizure ever, it lasts longer than five minutes, they are having back-to-back seizures with no

return to baseline, they have trouble breathing, do not regain consciousness after the seizure, or if they have sustained an injury that requires more than basic first aid.

**Constipation** occurs when a person has infrequent, difficult, or painful bowel movements. This can become life threatening as it can lead to bowel obstruction. For people with IDD, constipation is a common condition. Keeping a bowel chart can help with monitoring bowel habits and it may also be useful to implement a toileting schedule to help the person follow a bowel routine. Signs of constipation could include:

- Passing fewer than three stools a week
- Lumpy or hard stools
- Straining to have a bowel movement
- Bloating of the abdomen
- Difficulty passing gas

There are conditions that can also increase the risk of constipation, including neurological disorders, metabolic or endocrine disorders, gastrointestinal conditions, and aging. Reviewing a person's diagnoses and history can be helpful. Several medications can have side effects of constipation. These are some of the more common ones:

- NSAIDS
- Antihistamines
- Antidepressants
- Antipsychotics
- Diuretics
- Meds for Urinary Incontinence

- Iron Supplements
- Calcium Supplements
- Opioids
- Blood Pressure Medications
- Meds for Nausea

Therefore, reviewing current medications to determine if they are a factor can give insight into potential causes. If there are concerns regarding medications that a person is taking, check the medication guides that come with the medications or speak with the pharmacist. For someone experiencing constipation it is important to monitor dietary fiber and fluid intake. If a person is not taking in enough fiber and liquid, this can contribute to constipation. Incorporating regular physical activity can also help with constipation. This can also be challenging if a person has mobility issues. If a person is experiencing frequent episodes of constipation speak to their medical provider for guidance on the best way to manage it.

**Dehydration** is a loss of more fluids than a person is taking in. For people with IDD there can be several barriers and challenges to ensuring they have adequate fluid intake. Some individuals with IDD are at greater risk for dehydration and it can happen quickly. It can happen even more so in hot weather, during illness, or if someone is physically exerting themselves. Signs that may be noted in someone experiencing dehydration can include:

- Extreme thirst
- Less frequent urination
- Dark-colored urine
- Fatigue

- Dizziness
- Confusion
- Irritability
- Dry mouth and skin

Monitoring the color of someone's urine is a good indicator of hydration. The darker and more concentrated the urine the less hydrated a person is. Also, monitoring fluid intake can give a better insight into how much fluid a person is taking in. Encouraging fluids frequently throughout the day, as well as foods that have higher water content, such as watermelon, strawberries, lettuce, cucumbers, popsicles, and flavored gelatin can aid in preventing dehydration. Water is always the best option. Avoid caffeinated and alcoholic beverages, like soda pop, which can contribute to dehydration.

**Infection** occurs when a pathogen, such as bacteria, viruses, parasites, or fungi, invade the body and multiply. Monitoring for signs of infection will depend upon what type of infection it is and the ability of the body to fight off the pathogen. A person may experience fever, chills, vomiting, diarrhea, coughing, redness, swelling, warmth, pus, or oozing from the affected area. For people with IDD there may be other signs that may be more difficult to correlate with an infection, such as behavioral changes including aggression, withdrawal, changes in mental status-confusion, delirium, or disorientation. They may be lethargic or unwilling to participate in desired activities or daily routines. If there is any type of pain, the person may be bracing, guarding, or rubbing the area of discomfort. For someone with dental pain they may refuse to eat. Sometimes the person just does not seem like themselves. It may be difficult to recognize that there is an infection occurring if there are not obvious outward signs. That is why monitoring, documenting, and

making the medical provider aware of what is observed is essential, so that treatment of the infection is not delayed, and that it does not evolve into sepsis.

**Sepsis** is the body's severe reaction to an infection, causing a cascade of events throughout the body. If not treated promptly, it can rapidly result in tissue damage, organ failure, and death.

There are conditions that put people at risk for sepsis. It is more prominent in people over sixty-five, children under the age of one, people who have weakened immune systems, sepsis survivors, someone with a diagnosis of chronic health conditions, and medically fragile people with IDD.

Signs that may occur with sepsis can include:

- High heart rate
- Low blood pressure
- High temperature or a very low temperature
- Confusion or disorientation
- Lethargy
- Extreme pain or discomfort
- Shivering or complaint of feeling very cold
- Shortness of breath
- Clammy or sweaty skin

Monitoring and reporting the signs of sepsis, as well as any of the other signs of infection will be important to promptly communicate to the medical provider. The provider should also be made aware of any prior known history of sepsis. This condition is severe and life threatening, requiring immediate evaluation and treatment.



It may not always be obvious that someone with IDD is experiencing one or more of the fatal five conditions. It is essential that those who are supporting the person, as well as the person themselves are educated and aware of what common signs and symptoms associated with the “Fatal Five” conditions—aspiration, dehydration, seizures, constipation, and infection/sepsis may look like. Monitoring, documenting, and communicating with all involved in care can help to ensure overall well-being for people with intellectual and developmental disabilities, reducing the risks associated with these fatal five conditions.

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## Biography

**Jenifer Baker** has over 30 years of experience working with individuals who have intellectual/developmental disabilities (IDD) /Autism. She has spent the last nine years working as a Health Care Quality Nurse at Milestone HCQU West, where she focuses on improving physical and behavioral health care for self-advocates, as well as supporting families and caregivers on this journey. She is certified as a Developmental Disabilities Nurse and holds certification from the National Council of Certified Dementia Practitioners. Jenifer also serves as the President of the Board of Directors for Growing Together Aquaponics, a non-profit organization that provides job training, employment, and educational opportunities for individuals with IDD/Autism.

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## **Voices of Suicide**

**Heather McLean**

Suicide is one of the leading causes of death locally, nationally, and internationally. Suicide rates have increased by 2.6% from 2021 to 2022. According to the Centers for Disease Control and Prevention (CDC)<sup>1</sup>, 2022 statistics recorded the highest rates of suicides ever recorded in history. In 2022, 49,449 people died by suicide in the United States. On average, we lose 130 people to suicides every day in America. Suicide is the third leading cause of death for ages 10-24. Suicide has been referred to as the “silent epidemic” due to the stigma associated with suicide and mental health. The stigma with mental illness and suicide has created a barrier for people to reach out for help and to let others know they are struggling.

As a society, there was a time when we would only whisper the word cancer. The word cancer was associated with shame and embarrassment. When it comes to talking about cancer, we have come a long way in realizing we aren’t going to cause cancer or make it worse by talking about it. The pink ribbons have become synonymous with breast cancer, people raise lots of money for cancer research via social media and we openly discuss health habits and behaviors to try and prevent cancer. We should feel the same about suicide. Unfortunately, we have a long way to go with our comfort level in discussing and accepting mental health-related issues, especially suicide.

According to the CDC WONDER<sup>2</sup> report released in August of 2023, 12.3 million adults seriously thought about suicide, 3.5 million adults made a plan, and 1.7 million adults attempted suicide in 2021. Suicide rates among males continue to be four times higher than the rates among females. Males make up 50% of the population, but nearly 80% of the

suicides. Firearms continue to be the most common method used in suicides. Nationally and locally, firearms are used in more than 50% of suicides according to the CDC and 2022 Westmoreland County Coroner's Report.<sup>3</sup>

The aging population are at an exceptionally high risk of suicide. According to the 2022 Westmoreland County Coroner's Report,<sup>3</sup> suicides increased over 100% from 2021 to 2022 in the aging population. Some of the well-known risk factors in the aging population are the loss of a major relationship, particularly a spouse. Loss of mobility/loss of freedom due to loss of mobility and the onset of medical conditions or diagnosis of a terminal illness can be very big factors. The aging often feel that they have become a burden to others. Changes in medical conditions can be directly linked to depression. Often at a medical checkup, emotional issues are rarely addressed, leaving undiagnosed mental health concerns. Due to medical changes experienced by the aging, feelings of burdensomeness can put them at a very high risk for suicide.

The recent suicides over the last several years of some high-profile people like Robin Williams and Twitch have brought more attention to the suicide crisis in our country. According to the CDC<sup>2</sup>, we are currently losing about 130 people to suicide every day. Even though people are talking more about suicide than ever, we still have a lot of work to do. Suicide continues to be a national health care epidemic across the lifespan.

What is left behind in the aftermath of a suicide is a trail of broken hearts filled with many unanswered questions. Loved ones that are left behind grieving are called suicide loss survivors. It is said that between 48 million and 50 million people are thought to experience suicide bereavement every year.<sup>4</sup> A suicide loss survivor is at a four times higher risk of dying by

suicide. It also increases the risk of depression and feelings of guilt, shame, and rejection. Suicide loss survivors are also at a greater risk for increased psychiatric needs and interpersonal disruptions and isolation. All these risks are higher in Suicide Loss Survivors than in any other traumatic kind of death.

The voices of suicide span across many facets of life. From the voice of the attempt survivor to the voice of a loss survivor. From a treatment perspective of the mental health provider to the professionals responding to suicide. They all have a voice. Are we listening? Attempt survivors and loss survivors are sharing their stories. They are writing books, doing podcasts, and using social media as a platform.

There is power in sharing your story. It is a framework centered through heartache and resilience. Mental Health Professionals are now listening to people with lived experience and finding great insight from the stories being shared. We are learning from every story to help prevent future suicides and to comfort the grieving. Coping with such a profound loss is unique to every person. Survivors of suicide are not alone in their grief. Ray of Hope, Westmoreland County Suicide Prevention and Awareness<sup>5</sup> in partnership with Mental Health America of southwestern PA<sup>6</sup> hosts a monthly support group called Loved Ones Stolen by Suicide (LOSS). This support group is facilitated by three long-term suicide loss survivors. The group allows for sharing, support, and encouragement for anyone who has experienced the profound grief of losing a loved one to suicide.

Ray of Hope also hosts a suicide attempt survivor's support group called Hope and Healing, finding hope and support for those recovering from a suicide attempt. There are very few support

groups for suicide attempt survivors. This is a safe place to talk openly about suicide. Being able to share your attempt story can bring a sense of relief. This group offers a way for people to express their feelings that suicidal thoughts exist. It is okay to have times where we feel overwhelmed, and that suicide may feel like the only way out. Sharing these feelings can open the conversation for people who are feeling alone and feel that no one understands. They realize they are not alone, and many people do relate to how they are feeling. This brings hope and connectedness. Connectedness is the biggest protective factor against suicide.

Suicide Awareness and Prevention Education for first responders, medical personnel, and mental health care providers needs to become a common thread of lifesaving measures intertwined in the trainings they receive. Only 10% of mental health professionals are competent to deal with a suicidal crisis, and those are the experts we go to in a crisis.<sup>7</sup>

Ray of Hope provides free suicide awareness and prevention trainings called QPR. QPR stands for Question, Persuade, and Refer. QPR is an internationally recognized evidence-based suicide awareness and prevention training for anyone<sup>8</sup>. These trainings are offered to anyone in Westmoreland County at no cost to the attendee. QPR teaches how to ask the suicide question, how to encourage/persuade someone to get help, and know where to refer a person to the needed resources. Using QPR can save a life. More information can be found at [The QPR Institute](#).

The Ray of Hope, in partnership with the Westmoreland County Coroner's Office<sup>3</sup>, has started a LOSS Team. Their mission is to make connections and instill hope in those grieving the suicide loss of a loved one by providing support, comfort, and needed resources. The team is made up of community members and suicide loss survivors trained to reach out to newly bereaved suicide

loss survivors. This postvention response is also prevention for the newly bereaved loss survivors.

The LOSS Team model was developed by Dr. Frank Campbell at the Baton Rouge Crisis Trauma Center in 1998. The key to a LOSS Team is the connection made by a shared experience of a suicide loss. This creates an installation of hope, practical support, and connection to resources. The Ray of Hope, in partnership with the Westmoreland County BH/DS Office, invited Dr. Campbell to Westmoreland County in October of 2022 to provide a LOSS Teams training. That training began the journey to forming the county's LOSS Team. Westmoreland County is the 2<sup>nd</sup> county to have a LOSS Team in Pennsylvania.

The Ray of Hope looks for opportunities for people affected by suicide to share their stories. They held their annual conference November 17, 2023. The theme was "Sharing Saves Lives, The Power in Your Story." The keynote speaker was an attempt survivor and published author who shared his story of hope and resilience. The afternoon consisted of an attempt survivor panel that shared their lived experiences through the journey of their suicide attempt and finding hope and connection.

Recently, the Westmoreland County Behavioral Health Disability Services Office received a grant from the Pennsylvania Department of Human Services Office of Mental Health and Substance Abuse to provide specialized trainings to mental health professionals to enhance efforts in managing suicide risk by partnering with other organizations and first responders. This training is called CAMS-care (Collaborative Assessment and Management of Suicidality)<sup>9</sup>. This training will allow Certified Suicide Prevention Specialists to respond to different levels of crisis response within the first responder system and greatly enhance our efforts to save lives. CAMS



care is an evidence based, suicide focused treatment framework backed by 30 years of clinical research and six published randomized controlled trials. Giving providers tools to enhance their scope of practice is extremely important. This training will allow for 50 individuals in Westmoreland County to become Certified Suicide Prevention Specialists. Information can be found at [CAMS Care](#).

In Westmoreland County, the voices of suicide are being heard. Through our awareness and prevention efforts, education, support groups, LOSS Team, and other community events, lives are being saved. Stories are being shared. People are getting connected and finding hope. The voices of suicide are many. Their stories are still being written.

Westmoreland County has many resources to support our communities and those struggling with a mental health crisis. Westmoreland Community Action runs our local crisis hotline. The hotline answers calls 24 hours a day, seven days a week. They also have a mobile team that provides assessments based on the level of need of the caller. They can be reached by dialing 1-800-836-6010. A national resource is also available for immediate assistance. The 988 Suicide & Crisis Lifeline<sup>10</sup> provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, seven days a week, across the United States and its territories. If you or anyone you know is in a mental health crisis or in need of emotional support, there are a lot of resources available. The Westmoreland County Behavioral Health Disability Services (BH/DS) Office has a list of local providers. They can be reached at (724) 830-3617 or on the Westmoreland County Website<sup>3</sup>. It is important to remember that there is hope, there is help, and you are not alone in your struggles.

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## Biography

**Heather Mclean** began her career working in the mental health field 23+ years ago. Heather has been employed at MHA-SWPA since 2019 as their Outreach Coordinator. As part of her position as the Outreach Coordinator, Heather participates on numerous committees and boards. These committees include Ray of Hope Westmoreland County Suicide Awareness & Prevention Task force, CSAY-Counsel for Substance Abuse & Youth, HAWC-Hoarding Alliance of Westmorland County, and Steering Committee member for the Southwest Regional CIT Program. Heather currently holds an officer position on the state board of SPA-Suicide Prevention Alliance and on the Board and of Directors of Greater Things Ministries and Fight the Blight. Heather also works closely with the Westmoreland County BH/DS office coordinating lots of trainings and events. Heather has worked in suicide prevention since 2009. She has served as the Ray of Hope Chair since 2016. Her responsibilities include the oversight of 80+ task force members, multiple sub-committees, supervision of the task force coordinator, and Lead of the newly formed L.O.S.S. Team (Local Outreach to Suicide Survivors). Heather also facilitates the Hope & Healing support group for those recovering from a suicide attempt. Heather is the Westmorland County EBH (Emergency Behavioral Health) Coordinator that aids in the emotional response following a traumatic event. Heather is a certified QPR Gatekeeper Instructor, Certified CIT (Crisis Intervention Team) Coordinator, Certified YMHEA (Youth Mental Health First Aid) Instructor, Certified Bridges out of Poverty Instructor, and ASIST (Applied Suicide Intervention Skills Training) Trainer. Heather provides many trainings to schools, colleges/universities, community/social service agencies, businesses, medical personnel/first responders, and faith-based organizations. Heather is a 2002 honors graduate from Point Park University where she received her Bachelor of Science degree in criminology/criminal rehabilitation. Prior to that she attended Westmoreland Community College where she received an associate's degree in legal assisting/paralegal in 2000. Heather likes to spend free time mentoring youth at The Father's Heart Ministries. She also stays busy loving her two dogs, two children, and husband Troy.

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