Complex Mental Health Needs of People with IDD:
A Gap Analysis Framework

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Executive Summary

Between 30% and 55% of people with IDD (PwIDD) also have mental health conditions. Differences in the ways PwIDD communicate, misinterpreted behaviors, lack of financial resources, and lack of education among health care providers can make accurate diagnosis, access to services, and appropriate treatment challenging and affect the quality of services received. While common gaps in service are known, they are not well categorized or comprehensively described.

Efforts to address these gaps often fail to include the viewpoints of PwIDD. As a result, many programs fail to meet the critical needs they were designed to address and end up failing the people they were designed to support. As part of this project, self-advocates in Texas responded to an online needs assessment survey. Their responses indicate a high rate of depression (84%) and anxiety (49%), as well as psychotic disorder (27%), bipolar disorder (24%), post-traumatic stress (14%), substance abuse (11%), and eating disorder (3%). These co-occurring conditions impacted nearly every aspect of responding self-advocates' lives, including their important relationships (73%), physical health (68%), ability to think clearly or solve problems (60%), employment (57%), hopes or goals for the future (46%), housing (35%), safety (33%), finances (30%), support of children or elderly relatives (19%), and use of drugs or alcohol (16%). It is clear that the mental health needs of self-advocates here and around the world are complex and significant.

This comprehensive gap analysis framework identifies service gaps by area of practice, agents of potential change, affected populations, and needed and existing human and capital resources. This information has the power to enable all those working to improve mental health services and support for PwIDD to design and deploy potential solutions more efficiently and effectively.

The framework consists of five domains, each focusing on a specific aspect of the continuum of mental health care for PwIDD: Awareness, Access, Quality of Care, Diagnosis, and Treatment. These domains are described in more detail in the *Methodology* section. Each domain includes specific topics classified as either *Opportunities* or *Challenges*. *Opportunities* outline the specific programs, organizations, and policies that appear to work toward closing the gap for PwIDD and co-occurring mental health issues. *Challenges* summarize the deficits that persist, including lack of resources or education, overwhelmed systems, fragmented or inappropriate services, and negative attitudes that contribute to creating or maintaining the gap.

Each topic briefly describes audience groups for whom the topic might be most helpful, including self-advocates; family/friends/allies; service providers; health care providers; Intellectual and Developmental Disability, Behavioral Health, and Mental Health (IDD/BH/MH) agencies; and policymakers. Where applicable, relevant statistics quantify impact on/by specific issues, groups, settings, and policies.

The framework also includes two sections titled *Special Populations* and *Special Issues*. In our research, we found that some populations of PwIDD, such as those with specific diagnoses, living in specific locations (e.g., rural areas), or with diverse racial/ethnic backgrounds, are impacted differently from others across the spectrum of mental health. Additionally, special issues such as family stressors or trauma also impact people differently and require specific solutions. Finally, we recognized that, while still developing, research on the impact of Covid-19 and the efforts used to mitigate its spread needed special attention. In each of these sections, we describe these populations and issues.

Key Findings and Recommendations

Awareness

It appears that little is being done in the field to increase awareness of both the prevalence and presentation of mental health conditions in PwIDD. Yet, this lack of awareness is a barrier at almost every stage of mental health care. An important key to changing this trend is educating all stakeholders about mental health conditions in PwIDD and how to recognize the difference between IDD and mental health conditions. Additionally, normalizing mental health care and reducing the stigma and secrecy surrounding mental health conditions increases awareness and provides people opportunities to seek help without shame or embarrassment.

While much of the research focused on educating parents and caregivers to recognize and seek help for PwIDD and mental health conditions, this stakeholder group is perhaps least equipped in terms of time, energy, and finances to serve as a primary change agent. As such, incorporating training on effectively treating co-occurring conditions, including more effective diagnostic approaches and better communication strategies and processes, into professional preparation could make a significant impact in this area.

Access

The ability for PwIDD and co-occurring mental health conditions to access effective mental health care is hindered by multiple problems at every level, from systemic issues (e.g., waitlists and fragmentation of services) to pragmatic factors (e.g., lack of technology access and a dearth of qualified providers). In addition to addressing these issues individually, broad change can impact access to effective mental health care. For example:

- Stronger community living policies that support independent living within a supported community can provide needed services and support for PwIDD as well as alleviate overburdened caregivers who frequently make up for absent services.
- State Medicaid agency incentives and financial relief programs can lessen financial hardships that often work as the primary barrier to accessing services.
- Active recruitment of qualified mental health care providers who understand the intersection of IDD and mental health conditions as well as expanding training opportunities for those without necessary skills are important steps to eliminating the scarcity of health care providers.

Quality of Care

Perhaps one of the most disturbing aspects of care for PwIDD and co-occurring mental health conditions is the quality of the care they receive when they are able to access services. The field is fraught with fragmented services, discordant organizational policies among providers, services that fail to put the patient first, and service providers with attitudes and beliefs that undermine the care and support they are entrusted to deliver. Overcoming these obstacles will require dedication to making systemic changes.

Changes that can improve overall quality of care include integrated care and service coordination overseen by an outside entity. In addition, service provision that includes person-centered care and supports autonomy will allow PwIDD to have an active role in the planning and implementation of their

own care, which is a vital element to effective support and treatment. Education of health care providers on the intersectionality of PwIDD and mental health conditions as well as cultural awareness must take place to defeat biases that leave people receive poor medical care from physicians and support staff that is insensitive to their needs.

Diagnosis

The more accurate the diagnosis, the more effective treatment for mental health conditions can be. Unfortunately, almost none of the diagnostic tools currently used are designed for the specific needs of PwIDD experiencing mental health conditions. The lack of the proper tools combined with diagnostic approaches that are not sensitive to race, ethnicity, or disability leave people with incorrect or absent diagnoses. Diagnostic tools designed for this population along with the use of multidisciplinary teams for the assessment process and better education on racial-, ethnic-, and disability-sensitive diagnostic approaches can provide more accurate diagnoses and lead to better treatment.

Treatment

A striking element of treatment for mental health conditions in PwIDD is the level of misunderstanding that leads to inappropriate or unnecessary placement of patients. From short-term crisis placement to long-term institutionalization or foster care, both adults and children with IDD experiencing mental health conditions are frequently seen has having behavioral issues that require these placements. Situations such as overmedicating or incorrect medication, a lack of appropriate psychotherapy, and a lack of specialized crisis treatment programs exacerbate the problem. At all stages of mental health care, stakeholders must learn to distinguish behavior that is related to a co-occurring mental health condition from behavior related to an existing disability. Once an individual has been "tracked' into an inappropriate placement or course of treatment, it is extremely difficult for that course to be corrected.

Additionally, PwIDD are three to ten times more likely to be victims of abuse, which often leads to unrecognized trauma. Their response to this unrecognized trauma is, again, often misinterpreted as challenging behavior stemming from the disability. Trauma-informed care, proper crisis intervention preparation, specialized hospital crisis units, and appropriate therapeutic methods dramatically decrease what is seen as problem behavior and increase the well-being of those being treated. Trauma-informed care practices must be disseminated to stakeholders at all stages of mental health care.

Special Populations

The co-occurrence of IDD and mental health conditions create a unique situation that, alone, requires a specific approach to treatment and support. Within the IDD community, there are people with more specialized needs based on their experiences. These include people living in rural areas, PwIDD who are aging, racially- and ethnically-diverse PwIDD, and people with specific diagnoses such as Autism Spectrum Disorder or Down Syndrome. Each of these "identities" amplify challenges to receiving appropriate mental health care and require increasingly more sensitive diagnostic and care approaches. Autonomy and person-centered care represent promising approaches that can most accurately provide care to individuals.

Special Issues

PwIDD and mental health conditions and their families often face situations that compound their need for mental health treatment or require treatment based on their specific situation. For example, family

caregivers often encounter burnout which amplifies their own mental health needs. Families tend to be the "first line of defense" in ensuring self-advocates' mental health needs are addressed. In fact, of the self-advocates responding to this project's needs assessment survey, 61% reported that their families were their primary source of mental health assistance. Failure to include family support and alleviate family stressors in efforts to improve mental health care is likely to perpetuate the gaps identified in this framework.

Children with IDD face critical consequences when acute mental health needs are not detected or addressed. Children with IDD are at high risk of placement in residential facilities or foster care. These children face additional risks such as placement instability, inconsistent caregivers, abuse, and a path to the juvenile justice system. Public school systems that have appropriate supports in place, including an Individualized Education Plan that includes mental health needs and goals, are critical in keeping children out of these undesirable placements (where they are most likely to be re-traumatized).

In addition, the impact of Covid-19 on the mental health of PwIDD and their caregivers is only now becoming clear—and it is alarming. Research begun and completed between 2020 and the first quarter of 2021 indicates that PwIDD and their caregivers are much more likely (in many cases four or five times more likely) to suffer from major depression and anxiety due to Covid-19 restrictions than nondisabled people and those that care for them. And one study indicated that these conditions are reported at rates two to three times higher than pre-pandemic levels *in the same population*. These figures are corroborated by a needs assessment survey conducted for this project. Eighty-four percent of respondents reported suffering from depression and 49% from anxiety. Impacts touch nearly every aspect of mental health care and constitute a mental health care emergency situation.

Areas for Future Study

This comprehensive gap analysis framework highlights areas where more research is needed to better understand and support PwIDD and co-occurring mental health conditions. Overall, there is a dire need for better awareness across nearly every component of care. One way to raise awareness is through effective training in medical and nursing schools and higher education programs. All service providers and health care providers must learn about the intersectionality of IDD and mental health to better serve this population. It is important to research best practices for these programs.

All aspects of mental health care for PwIDD are magnified in intensity by the Covid-19 pandemic and the mitigation strategies used to contain it. At the same time, fewer reliable supports for both PwIDD and their caregivers are available. This represents a crisis that needs to be addressed immediately and significantly with research, resources, and efforts from every entity that serves PwIDD and their caregivers.

There is also an extreme lack of research on several areas of intersectionality, including race and ethnicity, gender identity, and sexual orientation. Studies in intersectionality show the compounding effects of multiple life situations and experiences on people. PwIDD and mental health conditions who also contend with any of these other areas of intersectionality most certainly require specialized treatment approaches. Little is known about how these aspects impact their lives and how they can best receive services and support. Due to this lack of knowledge, it is likely that those most in need of mental health care are least likely to receive it.

Most of the diagnosis and treatment protocols for PwIDD and co-occurring mental health conditions are not designed specifically for PwIDD. Research shows that tools, therapies, and medication protocols designed for the general public are not as effective for PwIDD. More research must be done to develop and validate diagnostic tools, adjust or redesign therapies, and understand the effects of medication on PwIDD.

Call to Action

The current state of affairs for PwIDD who experience mental health conditions is one filled with inappropriate care and treatment, unnecessary expenses, and often, avoidable placement in residential treatment, crisis treatment, or foster care. The caregivers and service providers who support PwIDD and co-occurring mental health conditions are often overwhelmed trying to fight against a system that does not provide what is necessary. Addressing the factors that have brought about this state of affairs can reverse this path and lead to improvements with sustainable, significant results.

However, it is apparent that the mental health conditions of PwIDD and their caregivers, post-pandemic, are significantly worse than when this project began, and that supports are more significantly lacking. Government agencies, institutions, and organizations must marshal financial and human resources now to hope to stem the tide of the mental health care emergency on the horizon.

PwIDD who have appropriate and supportive services for their mental health conditions can achieve more autonomy and improved quality of life. They are productive contributors to society in their neighborhoods, schools, jobs, and communities. Financial expenses will be reduced for PwIDD, their families, and the agencies who support them. Making the changes recommended in this framework will bring urgently-needed support to a large population of people who have historically been marginalized. With this support, PwIDD can more fully share their remarkable gifts with the community, resulting in better societal outcomes for all.

Methodology

A qualitative research design was used to explore and understand the contributing factors to a concerning gap of services for PwIDD and co-occurring mental health conditions. Research was conducted by a team of researchers and self-advocates over a nine-month period.

Sources

The goal of the research was to create a complete picture of the broad landscape of mental health care for PwIDD. To meet this goal, and because so little "scientifically-based" research is available on this topic, we included a wide variety of sources. When available, sources were taken from peer-reviewed journals. We also analyzed other types of sources including publications and websites from government, academic, and non-profit organizations.

We included analysis of Texas-based research as intended to infuse the framework with a more local perspective. However, it soon became clear that information about how framework topics were addressed in *practice* in Texas was lacking. We felt it would be beneficial to create a "Texas Practice" supplement to the framework that describes entities responsible for, programmatic efforts toward, and organizations supporting the mental health care of PwIDD in Texas with respect to each of the framework topics. This supplement gives the reader a perspective on how complex mental health needs are, or are not, being addressed in Texas. It also provides direction to project staff developing the identification and referral tool in subsequent years of this project.

In total, 129 resources were used in this project. While most of the sources were based in the United States, sources from Australia, the United Kingdom, and Israel were included where they provided a unique or more in-depth view of a particular topic. These nations are also known to be at the forefront of services for PwIDD. The following is a list of the types and number of resources used.

- Scholarly journals: Sixty-five sources retrieved from peer-reviewed journals.
- Magazines: One magazine used (*Social Work Today*).
- News Sources: One news source used (Genoa Healthcare).
- Government Publications: Eighteen government agency position papers that provide information and statistics on topics related to their work.
- Nonprofit Publications: Thirty-two non-profit organization papers or informational publications in support of their missions.
- Websites: Twelve websites providing an overview of issues related to the research or summarizing reports and papers produced by academic groups and non-profits working for mental health and/or PwIDD.

Research Process

We developed a research summary form with general categories we planned to explore, which were taken from, among other baseline sources, the 2019 Texas Health and Human Services *Statewide Behavioral Health Strategic Plan Update and IDD Strategic Plan Foundation.* As we reviewed sources, we created a summary form listing the source citation, key points organized by broad topic, and additional sources mentioned that should be added to source list. As research progressed, the topic list evolved

based on emerging themes and trends. For example, a planned topic on "healthcare costs" expanded to encompass separate topics on self-advocate and caregiver financial distress, state Medicaid agency incentives, and health insurance. As we began to find fewer resources appropriate to our specific audience (PwIDD with co-occurring mental health conditions), we began assembling the framework by synthesizing sources around key topics within the broad domains of mental health care.

Framework Domains

The core framework consists of five domains. Each domain focuses on a specific aspect of PwIDD's experience of mental health care, based on how a person typically progresses from understanding they have a mental health condition through gaining appropriate treatment. The five domains are outlined below.

- *Awareness*: This section addresses the existence of and understanding that mental health conditions significantly impact PwIDD, even more so than for people without disabilities. Often, these mental health conditions go unnoticed or are not addressed by the very communities that support PwIDD such as family, friends, service providers, and even self-advocates themselves.
- *Access*: This section explores a PwIDD's ability to find and receive appropriate mental health services. There are several challenges to accessing these services and these challenges generally are greater than available opportunities.
- *Quality of Care*: This section addresses broad themes that span different points in a PwIDD's journey to receive appropriate mental health care. Fragmentation of services, lack of training for treatment providers, and potential biases and negative attitudes towards PwIDD all impact the quality of care received from access through diagnosis and treatment.
- *Diagnosis*: This section describes the specific methods, tools, and approaches used to diagnose mental health conditions co-occurring in PwIDD. The gap analysis includes both the appropriate assessment tools and diagnostic processes as well as challenges that prevent accurate diagnosis.
- *Treatment*: This section includes both general approaches to treatment and specific practices for PwIDD. Due to a lack of knowledge in the field of appropriate treatment and trauma-informed care for PwIDD who have co-occurring mental health conditions, services are often inadequate or missing altogether.

Through the research process, we also found that specific groups of people or issues are impacted or addressed differently across the mental health care domains. We felt special attention to these populations and issues was warranted, creating two separate sections to address them.

- *Special Populations*: This section provides information on the diverse needs of PwIDD with co-occurring mental health conditions. PwIDD have unique experiences that require further specialized approaches to address their needs. Topics covered here address intersectionality in areas such as rural living, aging, racially- and ethnically-diverse people, people with specific disorders, and incarcerated people.
- *Special Issues*: This section addresses issues or settings that significantly or differently impact the mental health care of PwIDD. They may complicate access to care, or they may represent a systematic barrier to care. These topics include stressors on supporting family members and

caregivers, trauma and PTSD, treatment in school settings, and communal living or foster care settings.

Opportunities and Challenges

The first five domains each contain two sections labeled *Opportunities* and *Challenges*. Opportunities outline the specific programs, organizations, strategies, and policies implemented in the field that have some evidence of effectiveness in closing the gap for PwIDD and co-occurring mental health conditions. Opportunities provide a resource or model for what appears to be working well, allowing for others to replicate these successful methods.

Challenges summarize the deficits that create or maintain gaps such as lack of resources or education, communication challenges, overwhelmed systems, fragmented services, and negative attitudes. Challenges are typically recognized in many sources as problematic, but do not yet have workable solutions. They are valuable learning points for all those who work or live with PwIDD and co-occurring mental health conditions. Challenges also suggest areas in which additional research or field work is needed.

Audience Groups

Each framework topic lists one or more audience groups. The audience group specifies either the population(s) most impacted by the topic and/or the population(s) most likely to be able to effect change with respect to the topic. Often, more than one audience group is listed, as many mental health issues both impact and are in turn impacted by many stakeholders. Below are the definitions of the audience groups and a short description of why that audience group might be included with a topic.

- *Self-Advocates*: PwIDD who speak for themselves, make their own decisions, learn about and know their rights, and learn about and know how to find support that is appropriate for their own needs are identified throughout this framework as self-advocates. Self-advocates are listed as an audience because the topic directly relates to their daily living or to special circumstances that impact them directly.
- *Family/Friends/Allies*: People who support PwIDD in their day-to-day lives with no financial compensation are identified throughout this framework as family/friends/allies. These can be parents, siblings, spouses, friends, or any other person close to the self-advocate. Topics where family/friends/allies are listed often contain information about how this group can provide support or access to services or how they themselves can find support.
- *Service Providers*: People who provide services to self-advocates under a financial exchange outside of the healthcare system are identified throughout this framework as service providers. Examples of service providers include direct care staff, day habilitation staff, transportation drivers, vocational trainers, and respite caregivers. When service providers are included as an audience, the topic typically provides information about the type of services, quality of services, or access to services they provide.
- *Health Care Providers*: Professionals who provide formal medical or psychological services for a fee such as doctors, nurses, psychologists, or psychiatrists are identified throughout this

framework as health care providers. These topics typically provide information about the type of services, quality of service, or access to the services they provide.

- *IDD/BH/MH Agencies*: Agencies included in this audience provide state- or federally-funded services based on a specific need. IDD agencies provide services specific to intellectual and developmental needs. Behavioral Health (BH) agencies provide services for behavioral health needs. Mental Health (MH) agencies provide services for mental health needs. Topics for this audience may address types of services, quality, and access and may also include information about collaboration among these organizations.

- *Policymakers*: People or organizations that have the power to research, decide upon, and implement changes within organizations and governments are identified throughout this framework as policymakers. When policymakers are listed as an audience, the topics address important issues to consider when proposing, writing, or implementing policy.

Relevant Statistics

Several framework topics include a *Relevant Statistics* category. Where the research we analyzed quantified impact with data and statistics, we included that information. Not all topics include this section, as many sources provided anecdotal information or described broad impacts. Lack of statistical information may indicate an area ripe for future research. Relevant statistics were included in the framework to assist policymakers, advocacy groups, and other interested parties in understanding how to make effective impacts on these issues and in advocating for more and better mental health care services.

Remedies

Some framework topics include a *Remedies* section. This section is included when an opportunity identified in the research is directly related to a challenge identified. Not all challenges have remedies, but where a link between a gap and one or more potentially effective practices exists, remedies have been included. Often, remedies refer the reader to previous Opportunities sections to examine what has worked in some situations. At other times, remedies suggest steps that can be taken to improve specific challenges based on the research.

Special Populations/Special Issues

As previously described, some populations and issues relate to or are impacted by topics across the continuum of mental health care, and these are addressed in separate sections of the framework. Where a continuum framework topic intersects one or more *Special Populations* or *Special Issues* sections, we have included a notation. For example, in the *Access* section, we have included a challenge called *Technology Infrastructure*. Because this challenge more significantly impacts people living in rural areas, we have included a reference to the *Special Population* topic, *Rural Communities*. This enables the reader to access more information efficiently and to gain context for the topic.

How to Use this Framework

The research completed and documented in this framework describes aspects of the gap in services for PwIDD who have co-occurring mental health conditions across the mental health care continuum. Some sections are more relevant to specific groups or organizations. For example, *Lack of Technological Infrastructure* is typically a challenge associated with rural areas. Other topics provide solid guidance for anyone who works or lives with a person with these co-occurring conditions. For example, *Stigma and Secrecy* touches any person or group working to improve mental health care.

The framework was designed with a flexible format that allows readers to use it in a variety of ways. The *Framework at a Glance* section provides concise charts summarizing each domain of mental health. These charts demonstrate, for each opportunity and challenge, the stakeholder groups, special populations, and special issues associated with the topic. This section can be used to gain a broad view of the landscape.

Each major section of the framework provides more in-depth information, including a brief overview, a summary chart, and narrative text describing each opportunity and challenge more in depth. A reader can review the framework sections from beginning to end to get "big picture" of complex mental health needs. Or a reader can read specific sections of interest without losing any context.

We have also designed the framework to lend an organizational structure to entities—state agencies, nonprofit organizations, health care providers, support networks—that wish to evaluate their own policies and practices with respect to mental health care for PwIDD. This is the process we used to develop the Texas Practice supplement, and we encourage other organizations to engage in a similar process. Specifically, we:

1. Extracted each framework topic to create an outline format (with the understanding that we could refer to the original, complete framework for more detail about a given topic if needed).
2. Analyzed laws and regulations, formal and informal policies, state- and federally-funded agencies and their local counterparts, public and nonprofit organizations and projects/programs, and university programs that advanced or blocked effective mental health care with respect to each topic.
3. Summarized these efforts and provided point-of-use access to more information about the resources.

In this way, the framework can become a living document that compels entities to better understand the needs PwIDD have in terms of mental health care and to adapt their own systems and organizations to effect positive change.

Framework at a Glance

Awareness	Opportunities	Challenges	
	Caregiver Education	Lack of Knowledge	Stigma and Secrecy
Stakeholders			
Self-Advocates	●	●	●
Family/Friends/Allies	●	●	●
Service Providers	●	●	●
Health Care Providers		●	
IDD/BH/MH Agencies			●
Policymakers			●
Special Populations			
Rural Communities		●	●
Aging People with IDD			
Racially- & Ethnically- Diverse People with IDD			
People with Autism Spectrum Disorder			
People with Down Syndrome			
Incarcerated People			
Special Issues			
Family/Caregiver Stressors	●	●	
Covid-19	●		
Trauma & PTSD			●
Treatment in a School Setting			
Foster Care and Residential Facilities			

Access	Opportunities			
	Financial Relief	State Medicaid Agency Incentives	Recruitment of Mental Healthcare Professionals	Community Living Policies
Stakeholders				
Self-Advocates	●	●		●
Family/Friends/Allies	●	●		●
Service Providers				●
Health Care Providers			●	
IDD/BH/MH Agencies	●	●	●	●
Policymakers	●			
Special Populations				
Rural Communities			●	
Aging People with IDD	●			●
Racially- & Ethnically- Diverse People with IDD				
People with Autism Spectrum Disorder				
People with Down Syndrome				
Incarcerated People				
Special Issues				
Family/Caregiver Stressors	●	●		
Covid-19				
Trauma & PTSD				
Treatment in a School Setting				
Foster Care and Residential Facilities				

Access	Challenges				
	Provider Scarcity	Lack of Technological Infrastructure	Financial Distress	Insufficient Insurance Coverage	Waitlists
Stakeholders					
Self-Advocates	●		●	●	●
Family/Friends/Allies	●		●	●	●
Service Providers	●				
Health Care Providers	●	●			
IDD/BH/MH Agencies	●	●	●	●	●
Policymakers		●	●	●	●
Special Populations					
Rural Communities	●	●	●	●	
Aging People with IDD			●		
Racially- & Ethnically- Diverse People with IDD					
People with Autism Spectrum Disorder				●	
People with Down Syndrome					
Incarcerated People					
Special Issues					
Family/Caregiver Stressors			●	●	●
Covid-19		●	●		
Trauma & PTSD					
Treatment in a School Setting					
Foster Care and Residential Facilities					

Quality of Care	Opportunities					
	Service Coordination	Integrated Care	Multi-Disciplinary Training	Person-Centered Care	Practitioners' Cultural Competence	Autonomy
Stakeholders						
Self-Advocates	●	●		●		●
Family/Friends/Allies	●	●		●		●
Service Providers	●	●		●	●	●
Health Care Providers		●	●		●	●
IDD/BH/MH Agencies	●	●				●
Policymakers		●				●
Special Populations						
Rural Communities		●	●			
Aging People with IDD	●	●				
Racially- & Ethnically-Diverse People with IDD					●	
People with Autism Spectrum Disorder	●	●				
People with Down Syndrome						
Incarcerated People						
Special Issues						
Family/Caregiver Stressors	●	●				
Covid-19	●					
Trauma & PTSD		●	●	●		●
Treatment in a School Setting						
Foster Care and Residential Facilities					●	

Quality of Care	Challenges				
	Systemic Barriers to Integrated Care	Negative Attitude of Health Care Providers	Fragmentation of services	Lack of Specialized Training	Poor Provider Communication
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers	●	●	●	●	●
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies	●		●		
Policymakers	●				
Special Populations					
Rural Communities		●		●	
Aging People with IDD	●				
Racially- & Ethnically- Diverse People with IDD	●				
People with Autism Spectrum Disorder			●		●
People with Down Syndrome					
Incarcerated People					
Special Issues					
Family/Caregiver Stressors			●		
Covid-19					
Trauma & PTSD		●			
Treatment in a School Setting					
Foster Care and Residential Facilities	●				

Diagnosis	Opportunities		Challenges		
	Multi-Dimensional Assessment Process	Targeted Assessment Tools	Co-Occurring Conditions	Racially- and Ethnically-Insensitive Diagnostic Approaches	Disability-Insensitive Diagnostic Approaches
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers	●		●		
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies					
Policymakers					
Special Populations					
Rural Communities					
Aging People with IDD					
Racially- & Ethnically-Diverse People with IDD				●	
People with Autism Spectrum Disorder			●	●	
People with Down Syndrome					
Incarcerated People				●	
Special Issues					
Family/Caregiver Stressors					
Covid-19			●		●
Trauma & PTSD	●	●	●		
Treatment in a School Setting					
Foster Care and Residential Facilities				●	

Treatment	Opportunities				
	Telehealth	Appropriate Use of Medication	Psychotherapy	Restorative Integral Support Model	Crisis Behavior Intervention Services
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers	●		●	●	●
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies	●		●		●
Policymakers			●		
Special Populations					
Rural Communities	●				
Aging People with IDD					
Racially- & Ethnically- Diverse People with IDD					
People with Autism Spectrum Disorder		●			
People with Down Syndrome					
Incarcerated People					
Special Issues					
Family/Caregiver Stressors					
Covid-19	●				●
Trauma & PTSD		●	●	●	●
Treatment in a School Setting					
Foster Care and Residential Facilities					

Treatment	Challenges				
	Over- or Inappropriate Medication	Lack of Trauma-Informed Care	Lack of Specialized Hospital Units	Unnecessary Institution-alization	Inappropriate Out-of-Home Placement
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers		●		●	●
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies		●			
Policymakers		●			
Special Populations					
Rural Communities					
Aging People with IDD				●	
Racially- & Ethnically-Diverse People with IDD					
People with Autism Spectrum Disorder			●	●	
People with Down Syndrome					
Incarcerated People		●			●
Special Issues					
Family/Caregiver Stressors					
Covid-19	●				
Trauma & PTSD	●	●		●	
Treatment in a School Setting					
Foster Care and Residential Facilities					●

Awareness

One's understanding or knowledge of the existence of possible mental health struggles, disorders, or diagnoses for PwIDD defines awareness throughout this section. Awareness also includes the understanding that PwIDD are more likely than people without disabilities to have a mental health condition (Einfeld et al., 2011). Mental health conditions among PwIDD may go unnoticed by self-advocates, family members, friends, allies, and service providers for many reasons.

Little information was found in the literature to define gaps or opportunities beyond the general availability or lack of education for the stakeholders involved. However, awareness that the co-occurrence of IDD and mental health conditions is likely is a critical first step to getting help for these conditions. It is also important to note that awareness and understanding of and attitudes toward co-occurring IDD and mental health related issues impacts every section and topic in the framework.

Awareness	Opportunities	Challenges	
	Caregiver Education	Lack of Knowledge	Stigma and Secrecy
Stakeholders			
Self-Advocates	●	●	●
Family/Friends/Allies	●	●	●
Service Providers	●	●	●
Health Care Providers		●	
IDD/BH/MH Agencies			●
Policymakers			●
Special Populations			
Rural Communities		●	●
Aging People with IDD			
Racially- & Ethnically-Diverse People with IDD			
People with Autism Spectrum Disorder			
People with Down Syndrome			
Incarcerated People			
Special Issues			
Family/Caregiver Stressors	●	●	
Covid-19	●		
Trauma & PTSD			●
Treatment in a School Setting			
Foster Care and Residential Facilities			

Opportunities

Caregiver Education

Summary: Most PwIDD and mental health conditions do not present for mental health services, leaving caretaking to families and communities (Costello, & Bouras, 2006). In fact, of the Texas self-advocates responding to the needs assessment survey for this project, 61% reported their families were their primary source for mental health assistance. To be more prepared to recognize and care for comorbid mental health conditions in PwIDD, families and caregivers can take classes or receive training. For example, training can address:

- Recognizing comorbid conditions and why behavioral struggles may occur, de-escalating behavior while keeping family members and others safe, and planning ahead for possible crises (Utah Parent Center, 2013; Beasley & Hurley, 2007)
- Enhancing their own quality of life, safety, and wellness while caring for more effectively their loved one with a disability (National Association of State Mental Health Program Directors, 2017c)
- Navigating a complicated care system (National Association of State Mental Health Program Directors, 2017d)
- Finding support from a primary care physician, neurologist, psychiatrist, or psychologist (Reach Across LA, 2016)
- Finding support groups and respite care. (Utah Parent Center, 2013; Beasley & Hurley, 2007)

    Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers

    Relevant Statistics:

    o   PwIDD have 30% more mental health conditions than non-disabled people (Putnam, 2009).
    o   One study showed that 51% of PwIDD had poor or fair health and more than one third of adults with IDD did not have good physical or mental health compared to only 12% of the general U.S. adult population that reports poor or fair health (Magana et al., 2016).

    Special Population(s)/Issue(s): Family/Caregiver Stressors; Covid-19

Challenges

Lack of Knowledge

Summary: While between 10 and 60% of children and young adults with IDD also have mental health conditions (Einfeld et al., 2011), many self-advocates, family/friends/allies, service providers and health care professionals lack the knowledge to recognize mental health conditions or to distinguish symptoms of mental health conditions from those of IDD (Giuntoli et al., 2015; Putnam, 2009; Rural Health Information Hub, 2018; Hsieh et al., 2020). Failure to recognize or distinguish mental health conditions from IDD leads to undiagnosed mental health conditions and lack of effective treatment.

    Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers

Special Population(s)/Issue(s): Rural Communities

Stigma and Secrecy

Summary: Stigma surrounding healthcare is often based on fear, embarrassment, and lack of knowledge. Stigma in turn leads to secrecy. Fear of experiencing prejudice leads to hesitation to seek care. (National Association of State Mental Health Program Directors, 2004; Rural Health Information Hub, 2018). Normalizing mental health conditions and reducing stigma should be principal goals of system reform (National Association of State Mental Health Program Directors, 2004).

Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; IDD/BH/MH Agencies

Special Population(s)/Issue(s): Rural Communities; Trauma and PTSD

Access

The ability to enter into the mental healthcare system after one becomes aware of a co-occurring condition defines *access* in this section. Programs that provide financial assistance to PwIDD, increase the number and quality of mental health care providers, and promote overall wellbeing improve access to mental health care. However, challenges to access are highly prevalent for those with IDD and appear to outweigh the available opportunities. This is underscored by recent work to develop the Texas *Statewide IDD Strategic Plan*, which identified a lack of access to services and care for complex needs as significant gaps (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Access	Opportunities			
	Financial Relief	State Medicaid Agency Incentives	Recruitment of Mental Healthcare Professionals	Community Living Policies
Stakeholders				
Self-Advocates	●	●		●
Family/Friends/Allies	●	●		●
Service Providers				●
Health Care Providers			●	
IDD/BH/MH Agencies	●	●	●	●
Policymakers	●			
Special Populations				
Rural Communities			●	
Aging People with IDD	●			●
Racially- & Ethnically-Diverse People with IDD				
People with Autism Spectrum Disorder				
People with Down Syndrome				
Incarcerated People				
Special Issues				
Family/Caregiver Stressors	●	●		
Covid-19				
Trauma & PTSD				
Treatment in a School Setting				
Foster Care and Residential Facilities				

Access	Challenges				
	Provider Scarcity	Lack of Technological Infrastructure	Financial Distress	Insufficient Insurance Coverage	Waitlists
Stakeholders					
Self-Advocates	●		●	●	●
Family/Friends/Allies	●		●	●	●
Service Providers	●				
Health Care Providers	●	●			
IDD/BH/MH Agencies	●	●	●	●	●
Policymakers		●	●	●	●
Special Populations					
Rural Communities	●	●	●	●	
Aging People with IDD			●		
Racially- & Ethnically-Diverse People with IDD					
People with Autism Spectrum Disorder				●	
People with Down Syndrome					
Incarcerated People					
Special Issues					
Family/Caregiver Stressors			●	●	●
Covid-19		●	●		
Trauma & PTSD					
Treatment in a School Setting					
Foster Care and Residential Facilities					

Opportunities

Financial Relief

Summary: Loan repayment programs and state tax waivers may offer families some relief from the financial hardships that inhibit access to mental healthcare (Rural Health Information Hub, 2018; Jackson et al., 2015).

Audience(s): Self-Advocates; Family/Friends/Allies; Policymakers; IDD/BH/MH Agencies

Special Population(s)/Issue(s): Aging PwIDD; Family/Caregiver Stressors

State Medicaid Agency Incentives

Summary: State Medicaid agencies should have clear performance measures and payment incentives in contracts for Managed Care and Accountable Care Organizations (MCOs and ACOs). Contracts should describe service provider rules to ensure that PwIDD and mental health conditions have individualized care plans targeted to their unique service needs. Contracts must also ensure access to competent treatment and recovery support services. (American Association on Intellectual and Developmental Disabilities, 2013; Beasley & duPree, 2003; Pinals et al., 2017).

Audience(s): Self-Advocates; Family/Friends/Allies; IDD/BH/MH Agencies; Policymakers

Special Population(s)/Issue(s): Family/Caregiver Stressors

Recruitment of Mental Health Care Professionals

Summary: The lack of mental health care providers skilled in providing care to PwIDD is a significant challenge. To overcome this dearth, particularly in rural areas, communities can provide clinical rotations to grow the workforce (Rural Health Information Hub, 2018).

Audience(s): Health Care Providers; IDD/BH/MH Agencies

Special Population(s)/Issue(s): Rural Communities

Community Living Policies

Summary: Individuals experiencing social isolation are at risk for a number of negative health outcomes, including depression (Jackson et al., 2015). Community living policies that support walkability, mixed use communities, neighborhood safety, and accessible recreation and cultural activities can support the social integration of PwIDD. Additionally, strong, broad social networks can make it easier for adults with long-term care needs to find help with daily or occasional needs and relieve pressure on both family caregivers and public service systems (Jackson et al., 2015).

Audience(s): Self-advocates; Family/Friends/Allies; IDD/BH/MH Agencies; Policymakers; Service Providers

Relevant Statistics:

o   Depression was reported by 84% of respondents to the needs assessment survey conducted for this project, reinforcing that policies that combat social isolation are critical to Texas self-advocates.

Special Population(s)/Issue(s): Aging PwIDD

Challenges

Provider Scarcity

Summary: There is a shortage of qualified, trained health care professionals with in-depth knowledge of the specialized physical and mental health needs of PwIDD (Ward et al., 2010; Beasley & duPree, 2003). Multiple factors contribute to the scarcity of mental health providers in different areas, including low reimbursement rates, high no-show rates among mental health clients, and high numbers of uninsured patients (Rural Health Information Hub, 2018; Mental Health and Developmental Disabilities National Training Center, 2019; Ward et al., 2010).

Audience(s): Family/Friends/Allies; Self-Advocates; Health Care Providers; Service Providers; IDD/BH/MH Agencies

Relevant Statistics:

o   On the needs assessment survey of Texas self-advocates implemented for this project, 45% said the primary reason they were not receiving mental health assistance was that they could not find any help.

Special Population(s)/Issue(s): Rural Communities

Remedies:

Expanding training opportunities, technological infrastructure, and integrated care; and preparing settings to work with PwIDD could provide solutions to the provider scarcity problem (Mental Health and Developmental Disabilities National Training Center, 2019).

Related Opportunities: Recruitment of Mental Health Care Professionals

Lack of Technological Infrastructure

Summary: Telehealth may be a promising practice to provide mental healthcare for PwIDD as it can connect PwIDD and mental health conditions to providers with specialized training. However, improvement in technological infrastructure, particularly in rural areas, is needed to access telehealth providers (Mental Health and Developmental Disabilities National Training Center, 2019).

Audience(s): Health Care Providers; IDD/BH/MH Agencies; Policymakers

Special Population(s)/Issue(s): Rural Communities; Covid-19

Financial Distress

Summary: Financial distress including poverty and lack of or poor quality of health insurance is a significant barrier to mental healthcare. PwIDD are more likely to live at or below the poverty level due to a high unemployment rate, a lack of affordable housing, challenges with transportation, sometimes intensive and expensive medical needs, and limited government benefits. Financial distress also extends to caregivers, who often suffer significant financial burdens related to care for their loved ones and may have to move to find affordable services (Utah Parent Center, 2013).

Audience(s): Self-Advocates; Family/Friends/Allies; Policymakers; IDD/BH/MH Agencies

Relevant Statistics:

o   On the needs assessment survey of Texas self-advocates implemented for this project, 33% said the primary reason they were not receiving mental health assistance was that they could not afford it.

Special Population(s)/Issue(s): Rural Communities; Aging PwIDD; Family/Caregiver Stressors; Covid-19

Related Opportunities (See above): Financial Relief

Insufficient Insurance Coverage

Summary: Access to mental healthcare is confounded by lack of medical coverage for mental healthcare services (Rural Health Information Hub, 2018). Furthermore, the terms of Medicaid benefits are typically written for clients that do not have co-occurring conditions, which can limit access to effective services (Pinals et al., 2017).

Audience(s): Self-Advocates; Family/Friends/Allies; IDD/BH/MH Agencies; Policymakers

Special Population(s)/Issue(s): Rural Communities; Family/Caregiver Stressors; People with Autism Spectrum Disorder

Relevant Statistics:

o   Texas has the largest coverage gap in the country, with 766,000 residents ineligible for Medicaid and also ineligible for premium subsidies to offset the cost of private coverage in the exchange (Texas Council for Developmental Disabilities, 2016a).
o   In Texas, there has been a comparatively modest use of HCBS waiver funding. For example, in 2006, nationally, 83% of those served in developmental disability systems participated in an HCBS waiver program, compared to 54.7% in Texas (Agosta et al., 2008).

Related Opportunities: State Medicaid Agency Incentives

Waitlists

Summary: While Home and Community Based Service (HCBS) waivers and other community-based IDD services can provide financial aid and useful services, potentially eligible people may wait up to 12 years on interest lists for services and supports (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019). For example, recent Texas figures indicate there are over 7 times as many PwIDD on waiver waitlists than are currently receiving services. For those receiving waiver services as minors, there is also often a service gap between when they age out of their current waiver and when they reach the top of a waiting list for an adult waiver program (Nangle, 2018).

In addition, even when adults with IDD find and can afford qualified physicians, they remain on long waitlists for appointments (Ward et al., 2010).

Audience(s): Self-Advocates; Family/Friends/Allies; IDD/BH/MH agencies; Policymakers

Relevant Statistics:

o   On the needs assessment survey of Texas self-advocates implemented for this project, 11% said the primary reason they were not receiving mental health assistance was that they were on a wait list for help.

Special Population(s)/Issue(s): Family/Caregiver Stressors

Quality of Care

Quality of care refers to the overarching systems, approaches, and attitudes that impact services offered to PwIDD who are experiencing mental health concerns, from diagnosis through treatment. As PwIDD often require services from various providers due to complex needs and treatment plans, the fragmentation of such services, whereby providers are not in communication with one another regarding treatment, can result in difficulties in reaching treatment goals and getting proper care. In Texas, PwIDD migrate across multiple services and service delivery systems over the course of their lifetimes (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019). A survey assessing gaps in the Texas IDD system found care coordination to be a shortcoming. While the survey refers to IDD services in general, one might assume that this would apply as a gap in mental health service as well (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

A lack of training for treatment providers, as well as potential biases and negative attitudes towards PwIDD, can also present extensive quality of care challenges. Service structures, and the opportunities and challenges present in providing cohesive and helpful care, are presented in detail in this section.

Quality of Care	Opportunities					
	Service Coordination	Integrated Care	Multi-Disciplinary Training	Person-Centered Care	Practitioners' Cultural Competence	Autonomy
Stakeholders						
Self-Advocates	●	●		●		●
Family/Friends/ Allies	●	●		●		●
Service Providers	●	●		●	●	●
Health Care Providers		●	●		●	●
IDD/BH/MH Agencies	●	●				●
Policymakers		●				●
Special Populations						
Rural Communities		●	●			
Aging People with IDD	●	●				
Racially- & Ethnically-Diverse People with IDD					●	
People with Autism Spectrum Disorder	●	●				
People with Down Syndrome						
Incarcerated People						
Special Issues						
Family/Caregiver Stressors	●	●				
Covid-19	●					
Trauma & PTSD		●	●	●		●
Treatment in a School Setting						
Foster Care and Residential Facilities					●	

Quality of Care	Challenges				
	Systemic Barriers to Integrated Care	Negative Attitude of Health Care Providers	Fragmentation of services	Lack of Specialized Training	Poor Provider Communication
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers	●	●	●	●	●
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies	●		●		
Policymakers	●				
Special Populations					
Rural Communities		●		●	
Aging People with IDD	●				
Racially- & Ethnically- Diverse People with IDD	●				
People with Autism Spectrum Disorder			●		●
People with Down Syndrome					
Incarcerated People					
Special Issues					
Family/Caregiver Stressors			●		
Covid-19					
Trauma & PTSD		●			
Treatment in a School Setting					
Foster Care and Residential Facilities	●				

Opportunities

Service Coordination

Summary: Service coordination assists people through planning, coordinating, identifying, accessing, and monitoring services and supports to achieve the best quality of life and full community participation. When done properly, service coordination is person-centered, comprehensive, conflict-free, and effective in helping navigate multiple, complex systems. Service coordination should be independent from service delivery to ensure the service coordinator has no conflicts of interest and their role is separate from the delivery and/or payment of direct services. Access to service coordination should be available as necessary and on request to all PwIDD who have functional needs for an array of services and supports (Texas Council for Developmental Disabilities, 2016c).

Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers, IDD/BH/MH Agencies

Special Population(s)/Issue(s): People with Autism Spectrum Disorder; Aging PwIDD; Family/Caregiver Stressors; Covid-19

Integrated Care

Summary: Ninety-five percent of people with a primary developmental disability also experience secondary disabilities, including mental health conditions. The needs of PwIDD must be addressed holistically and integrated in the many areas of service available (Texas Council for Developmental Disabilities, 2014). Integrating care for PwIDD is more responsive to their often-complex needs and quality of life (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Integrated care services include primary care, specialist mental health services, employment, education and training, housing, habilitative services, behavioral supports, pharmacologic supports, environmental supports, financial supports, and entitlements and social services (National Health Service, 1999; Pinals et al., 2017). Integrated care has been shown to improve effectiveness and efficiency of healthcare (Jansen et al.,2006), and could result in reduced costs, increased identification of mental health conditions, and increased access to mental health services (Ervin et al., 2014; American Association on Intellectual and Developmental Disabilities, 2013). Practical considerations in the development of integrated care include longer appointment times, natural and non-fluorescent lighting, larger exam rooms, and specialized equipment (Ervin et al., 2014).

Audience(s): Self- Advocates; Family/Friends/Allies; Health Care Providers; Service Providers; IDD/BH/MH Agencies; Policymakers

Special Population(s)/Issue(s): Rural Communities; Trauma and PTSD; Aging PwIDD; People with Autism Spectrum Disorder; Family/Caregiver Stressors

Remedies:

In 2014, a Learning Community was created consisting of three state-based groups composed of multidisciplinary teams, which resulted in a comprehensive list of

recommendations when working with PwIDD and mental health conditions (National Association of State Mental Health Program Directors, 2015).

Multi-Disciplinary Training

Summary: Multi-disciplinary training includes training in treatment areas that represent different specialties yet together impact a person's overall health. People with the most challenging needs must be supported by the most skilled staff. Staff training should happen often, regularly, and focus on the issues that are related to people's needs for support and assistance, such as attachment and positive relationships, fears, diet, and depression (Moseley, 2004; Ahlstrom et al., 2020). Yet, there is a lack of training among education, health, community, and developmental service professionals in response to the mental health needs of PwIDD (American Association on Intellectual and Developmental Disabilities, 2013; Beasley, 2004; Beasley & duPree, 2003; Funk et al., 2008; Giuntoli et al., 2015; Hogg Foundation for Mental Health, 2015; Kalb et al., 2019; National Association of State Mental Health Program Directors, 2017a; Utah Parent Center, 2013).

Opportunities for training are available in many different settings and for different health care professionals. Board-certified behavior analyst training and a competency-based workforce development program, based on a biopsychosocial model developed by the National Association for the Dually Diagnosed (NADD) and National Association of State Directors of Developmental Disabilities Services (NASDDDS), could provide opportunities to grow the workforce available to PwIDD. Specialized programs in university systems such as Leadership Education in Neurodevelopmental and Related Disabilities (LEND) can prepare trainees from multidisciplinary professional paths to assume leadership roles in their fields to work with PwIDD. Other university-based programs, such as University Centers for Excellence in Developmental Disabilities (UCEDDs), provide interdisciplinary training to students and professionals who intend to provide support to PwIDD of all ages and their families (Pinals et al., 2017). Winters & Shelow (2016) found that forming a Professional Learning Community (PLC), through which webinars and collaborative learning on IDD and co-occurring mental health struggles took place, better prepared medical staff to work with PwIDD.

Audience(s): Health Care Providers

Special Population(s)/Issue(s): Rural Communities; Trauma and PTSD

Relevant Statistics:

Werner and colleagues (2013) found that, in a sample of 256 psychiatrists:
- o 90.2% of the psychiatrists surveyed agreed they lack specific training in diagnosis and treatment of PwIDD, and 86.9% agreed there is a need for training.
- o 34.3% reported unsatisfactory knowledge about psychotropic treatment and 40.0% about the diagnosis of psychiatric disorders among PwIDD.
- o Of 187 psychiatrists who answered a general psychiatry vignette, only four correctly diagnosed the three most likely diagnoses, 76 correctly diagnosed two, and 107 correctly diagnosed one or none. Of 54 who answered a child psychiatry vignette, 12 provided three correct diagnoses, 31 provided two, and 11 provided one.
- o 68.2% believed that PwIDD receive a relatively poor standard of psychiatric care. 94.4% agreed that there is a lack of skilled personnel, and 82.5% stated that adequate knowledge was lacking among mental health professionals.

Person-Centered Care

Summary: Person-centered care is a treatment approach that focuses on strengths, capabilities, and potential to contribute to the community instead of focusing on deficits (Pinals et al., 2017). PwIDD who can exert control over their lives will be more likely to be participatory and independent in community activities, have a higher quality of life, and will be more likely to be working for pay at higher wages. Person-centered behavioral interventions should be implemented prior to pharmacological interventions to treat symptoms of IDD and/or mental health (Pinals et al., 2017). The focus should be on what is important *to* PwIDD and mental health conditions instead of what is important *for* them (Moseley, 2004). As such, treatments for PwIDD that are proposed primarily for the convenience of the caregiver (such as medical procedures that interfere with typical growth and development) must be denied (American Association on Intellectual and Developmental Disabilities, 2013).

> Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers

> Special Population(s)/Issue(s): Trauma and PTSD

Practitioners' Cultural Competence

Summary: In building a workforce, it is important to hire people who represent the community they serve. It is also important to assure that employees are educated in cultural awareness, knowledge, and skill and are trained to promote cultural sensitivity (National Health Service, 1999; American Association on Intellectual and Developmental Disabilities, 2013; National Association of State Mental Health Program Directors, 2004).

> Audience(s): Health Care Providers; Service Providers

> Special Population(s)/Issue(s): Racially- and Ethnically-Diverse Populations; Foster Care and Residential Facilities

Autonomy

Summary: In an effort to honor autonomy, service providers should encourage questions, provide clear and understandable language, avoid coercive or deceitful language, provide full disclosure, and honor advance directives of PwIDD (American Association on Intellectual and Developmental Disabilities, 2013). Self-advocates should be involved at all levels of decision making, including developing their own plans of care and participating in broader policymaking initiatives (National Association of State Mental Health Program Directors, 2004; Texas Council for Developmental Disabilities, 2016b). In addition, surrogate decision-makers must follow the expressed wishes of the person. When the person's wishes are not knowable, the surrogate must follow the person's probable wishes, considering the person's known values, and act in the person's best interests (American Association on Intellectual and Developmental Disabilities, 2013).

> Audience(s): Self-advocates; Family/Friends/Allies; Service Providers; Health Care Providers; IDD/MH/BH Agencies; Policy Makers

> Special Population(s)/Issue(s): Trauma and PTSD

Challenges

Systemic Barriers to Integrated Care

Summary: PwIDD and mental health conditions are typically supported by different state agencies. These systems typically have different program structures, policies, and methods of service delivery, operate in accordance with separate regulations, employ differing eligibility criteria, and furnish supports through separate provider networks. IDD systems tend to work on a long-term basis while mental health systems tend to work on short-term limits. Importantly, PwIDD with co-occurring MH conditions are not homogeneous with each person having different capabilities, different methods of communication, and different life circumstances that significantly influence the nature of the treatment that is provided/needed (Moseley, 2004; Quintero & Flick, 2010; National Association of State Mental Health Program Directors, 2004). Even within integrated care, policies such as those mandated by Medicaid are often counterproductive, for example, not allowing billing on the same day by both physical and mental health providers or difficulties providing reimbursement to in-school service providers (Ervin et al., 2014).

> Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers; Service Providers; IDD/BH/MH Agencies; Policymakers
>
> Special Population(s)/Issue(s): Racially and Ethnically Diverse Populations; Aging PwIDD; Foster Care and Residential Facilities

Negative Attitude of Health Care Providers

Summary: Physicians lack sufficient training and exposure to PwIDD and both physicians and office staff can be insensitive to PwIDD's needs (Ward et al., 2010). Often, their negative attitudes and beliefs about PwIDD result in poor medical care and attention. Physicians may, for example, bypass their patient with IDD and communicate with parents instead. Parents report they often must act as liaisons and educators to the physicians, including providing strategies and interventions (Ward et al., 2010). Another study indicated that 40% of psychiatrists exhibited negative attitudes about treating PwIDD (Werner et al., 2013).

> Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers; Service Providers
>
> Special Population(s)/Issue(s): Trauma and PTSD; Rural Communities
>
> Relevant Statistics:

> - o Among a sample of 256 psychiatrists, 47.4% reported that there is prejudice among mental health workers towards PwIDD. In addition, 61.8% reported pity towards PwIDD and 59.3% expressed a preference for treating people other than PwIDD (Werner et al., 2013).
> - o Among a sample of 22 family physicians, 100% felt inadequately prepared to engage in the clinical care of adult PwIDD, including those physicians who chose to focus their practice on the care of adults with IDD (Wilkinson et al., 2012).

Fragmentation of Services

Summary: Failure to support people with dual or complex issues occurs as a result of organizational structures of service organizations, eligibility rules, clinical programs, and financing tactics related to IDD services being largely separate entities (Utah Parent Center, 2013). Since 2009, many organizations have narrowed eligibility criteria, and in some states, excluded diagnoses such as autism spectrum disorder from either mental health or developmental disability agency guidelines. State and mental health authorities serving PwIDD across the United States have widely differing structures including Medicaid plans, financing, organizational structures, and clinical programs (Pinals et al., 2017; Utah Parent Center, 2013). A lack of clarity of roles and responsibilities between caregivers can also result in poor service coordination and care (Giuntoli et al., 2015).

To fill gaps in service, agencies should collaborate and include self-advocates of all ages, their families/caregivers, and their service providers (Pinals et al., 2017; American Association on Intellectual and Developmental Disabilities, 2013; Beasley & duPree, 2003; National Association of State Mental Health Program Directors, 2004). Enhanced communication and coordination could ensure that services and supports are uninterrupted (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

> Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers; Service Providers; IDD/BH/MH Agencies

> Special Population(s)/Issue(s): People with Autism Spectrum Disorder; Family/Caregiver Stressors

Lack of Specialized Training of MH Professionals

Summary: While mental health professionals are usually trained as generalists, the treatment of people with dual diagnoses requires specific expertise, training, and experience. Training needs to address attribution of behavior to a person's disability rather than a potential mental health condition (i.e., diagnostic overshadowing). Training must also address the complex factors that may lead or contribute to mental health conditions in PwIDD. Lack of specialized training and other factors can contribute to ineffective treatment and inappropriate hospitalization (Moseley, 2004).

> Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers

> Special Population(s)/Issue(s): Rural Communities

Poor Provider Communication

Summary: Effective doctor-patient communication is essential for establishing strong patient relationships and working to eliminate health disparities faced by people with disabilities. However, having a disability has been found to be correlated with dissatisfaction and disappointment in provider encounters (VanZant & Perkins, 2015). While PwIDD and mild intellectual disabilities may use speech to communicate, those with moderate and severe intellectual disabilities may rely on family/caregivers for help (Chew et al., 2009; Utah Parent Center, 2013; Moseley, 2004). PwIDD may also have sensory issues which could impact their ability to communicate (Chew et al., 2009).

Physicians make assumptions about the communication skills and intellect of PwIDD, which results in a lack of direct communication. Physicians tend to talk to the person accompanying PwIDD instead of directly to the PwIDD (Ward et al., 2010). While there may be a need to rely on family/caregivers to obtain a medical history, it is important to not exclude PwIDD when gathering this information (Chew et al., 2009).

Consistently and directly interacting with patients builds rapport and encourages cooperation (Chew et al., 2009). Because PwIDD have varying degrees of communication abilities, they may draw from a range of communication methods known as augmentative and alternative communication strategies, such as communication boards and books, electronic devices, key word signing, facial expressions, and body language (Chew et al., 2009.) Formal Augmentative and Alternative Communication strategies can be barriers due to physical impairment limitations, omitted vocabulary in the augmentative and alternative communication system, or the service provider not giving the PwIDD enough time to understand and formulate answers (Chew et al., 2009). Principles for communicating with PwIDD include assuming competence, communicating directly, tailoring communication to the person's needs, and supporting communication efforts (Chew et al., 2009).

     Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers; Service Providers

     Special Population(s)/Issue(s): People with Autism Spectrum Disorder

Diagnosis

Diagnosis refers to the specific methods, tools, and approaches used to accurately diagnose mental health conditions co-occurring in PwIDD. Accurate, timely diagnosis is a critical first step in identifying and evaluating possible treatment options. Accurate diagnoses identify appropriate resources to aid a person experiencing dual conditions. Assessment tools and diagnostic processes provide opportunities for helpful treatment. However, many challenges exist that prevent accurate diagnosis, including—but not limited to—the inability for structured assessment instruments to be generalized and the lack of tools designed specifically for PwIDD.

Diagnosis	Opportunities		Challenges		
	Multi-Dimensional Assessment Process	Targeted Assessment Tools	Co-Occurring Conditions	Racially- and Ethnically-Insensitive Diagnostic Approaches	Disability-Insensitive Diagnostic Approaches
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers	●		●		
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies					
Policymakers					
Special Populations					
Rural Communities					
Aging People with IDD					
Racially- & Ethnically-Diverse People with IDD				●	
People with Autism Spectrum Disorder			●	●	
People with Down Syndrome					
Incarcerated People				●	
Special Issues					
Family/Caregiver Stressors					
Covid-19			●		●
Trauma & PTSD	●	●	●		
Treatment in a School Setting					
Foster Care and Residential Facilities				●	

Opportunities

Multi-Dimensional Assessment Process

Summary: Effective assessment to identify comorbid conditions and indicate treatment includes a variety of factors. Quality of assessment is also enhanced when it is done with a multidisciplinary team (National Health Service, 1999; Utah Parent Center, 2013; Bouras et al., 2001) as assessment services may cover physical, psychiatric, psychological, and social functioning of PwIDD. In addition, needs stemming from co-morbidity and personal circumstances, including family and caregivers, housing, financial, and occupational status provide useful information for diagnosis and treatment.

Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers; Service Providers

Special Issue(s): Trauma and PTSD

Targeted Assessment Tools

Summary: While diagnosis of a mental health condition in a PwIDD can be challenging, there are a variety of assessment tools specific to identifying comorbid conditions. The literature consistently recommends the use of a biopsychosocial assessment, which is based on a model that examines the connection of biology, psychology, and social factors. (Putnam, 2009). These types of assessments include

- Impact of Event Scale–Intellectual Disabilities (IES-IDs) (Wigham & Emerson, 2015);
- Aberrant Behavioral Checklist;
- Assessment for Dual Diagnoses;
- Developmental Behavioral Checklist-Parent/Caregiver or Teacher;
- Emotional Problems Scales-Self Report and Behavior Rating Scales;
- Reis Scales for Children's Dual Diagnoses;
- Devereux Scales of Mental Disorder; Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD; Putnam, 2009); and
- Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders (CAPs-IDD; Zeilinger et al., 2013).

In addition to using these diagnostic tools, it is important to be aware that because of the higher rates of exposure to traumatic events, PwIDD are at increased risk of developing Post-Traumatic Stress Disorder (PTSD). Therefore, screening for PTSD is necessary for more directed treatments and improvement in behavior (Bedard, 2013; Pinals et al., 2017; National Association of State Mental Health Program Directors, 2017b; Texas Health & Human Services, n.d.).

Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers

Special Issue(s): Trauma and PTSD

Challenges

Co-Occurring Conditions

Summary: Co-occurring conditions can make it difficult to accurately diagnose mental health conditions in PwIDD (Carvill, 2001; Marcal & Trifoso, 2017; Pinals et al., 2017; Utah Parent Center, 2013). For example, sensory deficits, such as hearing loss or visual impairment, go undetected in PwIDD despite occurring in greater numbers among PwIDD. These sensory deficits can make it difficult to identify mental health conditions. In addition, caregivers and practitioners may interpret behavioral symptoms as part of the IDD rather than recognizing an additional disability or condition (diagnostic overshadowing) (Carvill, 2001; Marcal & Trifoso, 2017). Mental health conditions may also manifest differently in PwIDD and may be misdiagnosed (Pinals et al., 2017).

Audience(s): Family/Friends/Allies; Service Providers; Health Care Providers

Special Population(s)/Issue(s): People with Autism Spectrum Disorder; Trauma and PTSD; Covid-19

Relevant Statistics:

o   Hearing loss is at least 40 times greater in PwIDD (Carvill, 2001; Pinals et al., 2017)
o   Vision impairment went undetected in 92% of people with severe/profound IDD (Pinals et al., 2017).
o   More than 70% of the people referred for dual diagnosis evaluation are found to have one or more medical problems which contribute to their mental health problems. It is now believed that about 75% of behavior problems in PwIDD have a connection to some type of physical condition (Utah Parent Center, 2013).
o   Approximately one-third of children found to have a psychiatric disorder had previously been examined by a child psychiatrist and indicated a previously unrecognized need for these services (Stomme & Diseth, 2000).
o   PwIDD are at least as likely, if not more likely, than the general population to develop depression, with estimates ranging from 2.2% to 15.8%, and anxiety, with estimates ranging from 3.8% to 17.4%. It is also estimated that these ranges are underestimates due to diagnostic challenges (Hsieh et al., 2020).
o   Depression was reported by 84% and anxiety of was reported by 49% of respondents to the needs assessment survey conducted with Texas self-advocates for this project.

Remedies: See opportunities section above.

Racially- and Ethnically-Insensitive Diagnostic Approaches

Summary: Self-advocates from racially-diverse communities often report that mental health assessments and treatment are sometimes undertaken from perspectives that are not understanding of ethnicity and should include considerations for that person's culture, race, and disability. (National Health Service, 1999).

Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers

Special Population(s)/Issue(s): Racially- and Ethnically-Diverse Populations; Incarcerated People; People with Autism Spectrum Disorder; Foster Care and Residential Facilities

Remedies: See Culturally Competent Practitioners and Assessment sections.

Disability-Insensitive Diagnostic Approaches

Summary: PwIDD are a heterogeneous population, and the application of measurement techniques developed for the general population is problematic (Costello & Bouras, 2006). For PwIDD who are moderately or more profoundly affected, it is not easy to rely on traditional assessments such as mental status exams (Putnam, 2009). Some issues practitioners face when trying to diagnose PwIDD and mental health conditions include

- thinking a behavior is learned rather than a symptom of a mental health condition.
- thinking an issue is related to IDD rather than a mental health condition.
- not recognizing that limited social experiences can look like a mental health condition, and vice versa.
- not recognizing that non-typical behavior that is common for that person may become exaggerated during stress and look like a mental health condition.
- not recognizing a person's inability to cope with stress can lead to anxiety-induced behavior that looks like a mental health condition.
- failure to account for the impact of impoverished life experiences and communication deficits.
- failure to recognize that complex conditions may occur at the same time.
- disturbed or regressed behaviors.
- physical signs and complaints such as headaches and abdominal pains.
- onset or increases in specific maladaptive behaviors such as screaming, aggression, and self-injury; and misidentification of non-specific, stress-induced loss of adaptive functioning (Costello & Bouras, 2006; Putnam, 2009).

Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers

Special Population(s)/Issue(s): Covid-19

Treatment

Treatment refers to both general approaches to treatment and specific methods and/or protocols. Treatment options for PwIDD and mental health conditions range from behavioral intervention and pharmacological resources, to crisis services and psychotherapy. However, many services have shortcomings due to a lack of knowledge surrounding the treatment of co-occurring disorders and trauma-informed care for PwIDD. While general structures are in place to treat mental health concerns, such services are often not specifically informed by or equipped to work with PwIDD. For example, a Texas survey assessing gaps in the IDD system found evidence-based practices in mental health care access to be a shortcoming (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Treatment	Opportunities				
	Telehealth	Appropriate Use of Medication	Psychotherapy	Restorative Integral Support Model	Crisis Behavior Intervention Services
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers	●		●	●	●
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies	●		●		●
Policymakers			●		
Special Populations					
Rural Communities	●				
Aging People with IDD					
Racially- & Ethnically- Diverse People with IDD					
People with Autism Spectrum Disorder		●			
People with Down Syndrome					
Incarcerated People					
Special Issues					
Family/Caregiver Stressors					
Covid-19	●				●
Trauma & PTSD		●	●	●	●
Treatment in a School Setting					
Foster Care and Residential Facilities					

Treatment	Challenges				
	Over- or Inappropriate Medication	Lack of Trauma-Informed Care	Lack of Specialized Hospital Units	Unnecessary Institution-alization	Inappropriate Out-of-Home Placement
Stakeholders					
Self-Advocates	●	●	●	●	●
Family/Friends/Allies	●	●	●	●	●
Service Providers		●		●	●
Health Care Providers	●	●	●	●	●
IDD/BH/MH Agencies		●			
Policymakers		●			
Special Populations					
Rural Communities					
Aging People with IDD				●	
Racially- & Ethnically-Diverse People with IDD					
People with Autism Spectrum Disorder			●	●	
People with Down Syndrome					
Incarcerated People		●			●
Special Issues					
Family/Caregiver Stressors					
Covid-19	●				
Trauma & PTSD	●	●		●	
Treatment in a School Setting					
Foster Care and Residential Facilities					●

Opportunities

Telehealth

Summary: Telehealth is the practice of providing patient care, education, and other health administration services through telecommunication options such as videoconferencing, the internet, and wireless communications. Patients receiving hybrid care of telepsychiatry with in-person visits experience greater access to care compared to patients receiving in-person care only (Genoa Healthcare, 2019). Telehealth is a promising strategy for expanding access to mental healthcare in areas with scarce services (Rural Health Information Hub, 2018).

> Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers; IDD/BH/MH Agencies

> Relevant Statistics:

> o   On the needs assessment survey of Texas self-advocates implemented for this project, 64% said they primarily receive mental health care remotely.

> Special Population(s)/Issue(s): Rural Communities; Covid-19

> Relevant Statistics:

> o   Patients utilizing telehealth were seen seven days sooner and were 34% more likely to have regular follow-up visits when combined with in-person care (Genoa Healthcare, 2019).
> o   On the needs assessment conducted for this project, the majority of people said they received help at home remotely (Phone Zoom, FaceTime, Skype, Teams) (64%).

Appropriate Use of Medication

Summary: Short-term mental health conditions can usually be treated with a combination of drugs provided by the primary care physician and psychotherapy provided from specialized services (National Health Service, 1999). Pharmacology has been shown to be especially helpful for people experiencing insomnia, depression, suicidal ideation, and panic attacks (Bedard, 2013). A psychiatric evaluation can determine if medication is appropriate and follow-up interviews can monitor the person's response to various pharmaceutical treatments (Utah Parent Center, 2013). Psychotropic medications should only be used with PwIDD within a multidisciplinary model and not in isolation of other treatments (Putnam, 2009). Side-effects and long-term effectiveness need further study (Pinals et al., 2017). Before prescribing medication, the following should be evaluated.

- Medical conditions
- Psychosocial and environmental conditions
- Health status and history
- Current medications
- Psychiatric diagnosis
- History of previous interventions and their results
- Functional analysis of behavior (Putnam, 2009)

Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers

Relevant Statistics:

o On the needs assessment survey of self-advocates implemented for this project, 79% indicated that they were on medication for mental health needs (although the survey did not probe the perceived appropriateness of their medication use).

Special Population(s)/Issue(s): People with Autism Spectrum Disorder; Trauma and PTSD

Psychotherapy

Summary: Psychotherapy can be effective for people with mild developmental disabilities (Putnam, 2009), but such therapy must be modified to address specific issues, such as dependency, and involve others in the treatment process. Short-term therapeutic approaches may not benefit PwIDD (Putnam, 2009). Policymakers should be aware that psychotherapy can take longer for PwIDD, and coverage should reflect these needs (Bedard, 2013).

The following specific approaches have been found to be beneficial in some settings.

- Cognitive-behavioral therapy, for depression, especially for PTSD, OCD, and anxiety (Bedard, 2013)
- Mindfulness-based cognitive behavioral therapy, especially for depression, PTSD, OCD, and anxiety (Wigham & Emerson, 2015)
- Problem Solving Skills Training (Putnam, 2009)
- Eye movement desensitization and reprocessing treatment, especially for PTSD and trauma (Wigham & Emerson, 2015)
- Narrative approaches, including life story books, multisensory storytelling, reminiscence-based interventions, and narrative therapy (Bedard, 2013)
- Psychoeducation on topics such as sexuality, social norms, the court system, consequences for actions, gender reassignment surgery, and how to deal with anxiety attacks (Bedard, 2013)
- Solution-focused brief therapy, especially for dealing with loss (Bedard, 2013)
- Coping technique (for example, "the shield," which consists of exposure, stress reduction techniques, and modified cognitive techniques; Fernando & Medlicott, 2009)

Effective treatment for PwIDD must also include support and education services for families and caregivers (Kliethermes et al., 2004).

Audience(s): Self-advocates; Family/Friends/Allies; Health Care Providers; Service Providers; IDD/BH/MH Agencies; Policymakers

Special Population(s)/Issue(s): Trauma and PTSD

The Restorative Integral Support Model

Summary: This model was developed for social service agencies helping people undergoing multiple problems that have a history of adverse childhood experiences. The Restorative Integral Support model acknowledges the role of early-life adversity, including developmental impact, to mobilize resilience and

recovery efforts. The principal idea behind the RIS model is to develop a culture of recovery that fosters social connections (Marcal & Trifoso, 2017).

> Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers; Service Providers

> Special Population(s)/Issue(s): Trauma and PTSD

Crisis Behavior Intervention Services

Summary: Crisis prevention planning—creating a plan to help predict, prevent, and plan for a mental health crisis—assists the person and those who provide support to them to better cope in times of difficulty. Five goals of the crisis prevention planning process are

- reaching an understanding regarding communication of needs through maladaptive behaviors,
- developing/improving upon coping strategies for the person and the family caregiver,
- preventing the system from going into crisis,
- delineating roles and responsibilities for specific professionals and service providers, and
- simplifying access to services (Beasley & Kroll, 1999).

Crisis intervention is a short-term solution for stabilizing a mental health crisis. Crisis intervention teams should be placed within local authorities to provide supports and services to assist people and families when a PwIDD is experiencing a mental health crisis. Crisis respite (emergency short-term, residential crisis treatment), intensive in-home support, and other crisis intervention services should be available. Crisis teams must be trained in both Trauma-Informed Care (TIC) and person-centered practices (Hogg Foundation for Mental Health, 2015).

The START (Systemic, Therapeutic, Assessment, Respite and Treatment) personal support plan is one example of a crisis prevention and intervention plan (Beasley & Kroll, 1999). The START program has shown improvement in mental health symptoms, reduction in hospitalizations/emergency room visits, and an increase in positive caregiver experiences with service providers (Kalb et al., 2019).

> Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Healthcare Providers; IDD/MH/BH Agencies

> Special Population(s)/Issue(s): Covid-19; Trauma and PTSD

> Relevant Statistics:

> o A survey assessing gaps in the Texas IDD system found crisis intervention to be a shortcoming. (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Challenges

Over or Inappropriate Medication

Summary: Medication management for PwIDD is more challenging than with the general population for several reasons. First, PwIDD are at a higher risk for side effects (Putnam, 2009). Evidence confirms that

a variety of side effects have been noted following the use of antipsychotic medication in particular, including somnolence, extrapyramidal symptoms (e.g., tremor, slurred speech, dystonia, anxiety, distress, paranoia, etc.), increased prolactin concentrations, significant weight gain and cardiovascular dysfunction (McQuire et al., 2015). Polypharmacy, or being prescribed multiple medications, can exacerbate drug interactions (Pinals et al., 2017; Putnam, 2009; Utah Parent Center, 2013).

In addition, over-medication may mask a real mental health need that requires assessment, diagnosis, and perhaps a different regimen of medication. It should also be noted that studies have focused on pharmacological interventions with adults, which does not provide solid grounding for such interventions to be used with children (Pinals et al., 2017).

Audience(s): Self-Advocates; Family/Friends/Allies; Health Care Providers

Special Population(s)/Issue(s): Trauma and PTSD; People with Autism Spectrum Disorder; Covid-19

Relevant Statistics:

- Off-label prescribing, prescribing medications outside of FDA indication, might be as high as 46% in PwIDD (Pinals et al., 2017; McQuire et al., 2015).
- National Core Indicators published a report on the use of medications in public IDD systems. 53% of 8,390 adults studied were taking meds to address mood, anxiety, or psychosis/behavioral challenges/both psychosis and behavioral challenges. Those using medications were slightly older, more likely to be white, live in group homes, be in poorer health, use tobacco products, and more likely to have autism spectrum disorder. Amongst those taking medications for mood, anxiety, or psychotic disorders, 41% did not have a psychiatric diagnosis. 8% of those whose evaluations showed no need for behavioral supports were taking prescribed medications for challenging behavior, and within that 8%, 18% were determined to not need behavioral supports. This scenario highlights the complexity of the issue of treating PwIDD with medication and risking undertreating an actual, comorbid psychiatric disorder vs. inappropriately medicating a behavioral issue (National Core Indicators, 2012; Pinals et al., 2017).
- The majority of Texas self-advocates responding to this project's needs assessment survey (79%) indicated that they were on medication for their mental health condition(s), although conclusions cannot be drawn regarding whether their medication was appropriate.

Remedies: See Opportunities section above.

Lack of Trauma-Informed Care

Summary: Trauma-informed care has received little attention as an approach to supporting PwIDD, a population historically having one of the highest rates of abuse (Bedard, 2013). This approach can alleviate suffering, increase rates of recovery, and improve practices in the IDD and MH fields (Hogg Foundation for Mental Health, 2015). Some PwIDD have a limited ability to communicate about their trauma combined with limited social skills. This combination can lead to difficulty integrating their awareness of the trauma, which can result in behavioral aggression. Being aware of trauma/PTSD as a cause of behavioral aggression can lead to more direct treatment and improvement of behavior (Pinals et al., 2017; Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

PTSD and other trauma-related psychological disorders may be miscategorized as challenging behavior or misdiagnosed as psychosis. Where behavior is framed as problematic or challenging, a person may be viewed only as a perpetrator rather than having been a victim in the past, and management may be more punitive than therapeutic (Wigham & Emerson, 2015). Being categorized as having challenging behaviors can push a PwIDD out of their living situation, which may add to their stress and also reduce opportunities for information sharing by disrupting support systems with families, friends, and services. Trauma-informed care training should be required for all staff in state supported living centers, intermediate care facilities for PwIDD and community group homes; including management, supervisory staff, mental health professional staff, training staff and direct care workers (Hogg Foundation for Mental Health, 2015; Keesler, 2020).

Audience(s): Self-Advocates; Families/Friends/Allies; Service Providers; Mental Health Care Providers; IDD/BH/MH Agencies; Policymakers

Special Population(s)/Issue(s): Trauma and PTSD; Incarcerated People

Relevant Statistics:

- PwIDD are anywhere from 3 to 10 times more likely to experience physical abuse, neglect, and/or sexual abuse in their lifetime (Bedard, 2014; Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).
- 70% of respondents with IDD reported having been a victim of abuse, and 90% of them reported experiencing abuse on multiple occasions (Hogg Foundation for Mental Health, 2015).
- Exposure to environmental stressors (i.e., poverty, exposure to violence, social isolation) may be higher in PwIDD, and exposure for at least six months can lead to trauma. Thus, PwIDD may be at increased risk of developing PTSD (Pinals et al., 2017).
- Trauma from abuse and neglect has detrimentally affected the development and transition to independence of youth with intellectual disabilities and increased the risk of sexual and violent offending. Childhood adversity has been linked to substance misuse, obesity, and depression and suicide (Wigham & Emerson, 2015).

Remedies: See Training section above.

Lack of Specialized Hospital Units

Summary: Generally, psychiatric hospitalization only occurs when a person is suicidal, is attempting to hurt themselves, or is a danger to or is threatening to hurt others (Reach Across LA, 2016). General units typically have staff that are not trained or experienced in assessment and treatment of PwIDD and co-occurring mental health conditions. In general units, PwIDD are at higher risk of exploitation by other patients (Siegel et al., 2012). For those that need psychiatric hospitalization, research has shown that units specialized in treatment for PwIDD and co-occurring mental health conditions likely provide better psychiatric care for this population.

Audience(s): Self-Advocates; Families/Friends/Allies; Health Care Providers

Special Population(s)/Issue(s): People with Autism Spectrum Disorder

Relevant Statistics:

- o 54% of PwIDD receiving services in state psychiatric hospitals are served in general psychiatry units, while 20% receive treatment in units designed especially for people with developmental disabilities, developmental disorders, or traumatic brain injury.
- o 80% of PwIDD in state psychiatric hospitals have a mental health co-occurring condition, but only 7% are served in units specializing in treatment for both conditions (National Association of State Mental Health Program Directors, 2004).

Unnecessary Institutionalizations

Summary: Both long-term and end-of-life planning needs to take place to prevent unnecessary placement in an institution, provide opportunities for choice and self-determination, and ensure that PwIDD have the highest quality of life (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019). Negative life events are significantly associated with self-injurious, aggressive, destructive, and stereotyped behaviors, and service providers must limit exposure to them. Where events are unavoidable, service providers must support the person through the event compassionately with a focus on their mental and physical well-being and providing behavioral intervention rather than medication (Bond et al., 2019).

PwIDD are anywhere from 3 to 10 times more likely to experience physical abuse, neglect, and/or sexual abuse in their lifetime (Bedard, 2013; Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019), which may be related to institutionalization, restraint and seclusion, extended hospitalizations, abandonment, bullying, and other forms of maltreatment. There is evidence that PwIDD with problematic behavior are more likely to utilize expensive hospital emergency rooms during times of difficulty when there are no available alternatives, which would be reduced with a coordinated care system (Beasley & duPree, 2003; Beasley & Hurley, 2003).

Audience(s): Self-Advocates; Families/Friends/Allies; Health Care Providers; Service Providers

Special Population(s)/Issue(s): Trauma and PTSD; People with Autism Spectrum Disorder; Aging PwIDD

Inappropriate Out-of-Home Placement of Children and Youth

Summary: According to the American Academy of Pediatrics Council on Children with Disabilities, children with IDD are at higher risk of out-of-home placement than other children and are particularly at higher risk of placement in residential facilities (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019; Lowe et al., 2007; National Association of State Mental Health Program Directors, 2015; Jacobstein et al., 2007). In addition, many children with co-occurring mental health conditions may be tracked into the juvenile justice system rather than the mental health system. This is a greater risk for children of low socioeconomic status or those who are Black or Latinx (Jacobstein et al., 2007).

Audience(s): Self-Advocates; Families/Friends/Allies; Health Care Providers; Service Providers

Special Population(s)/Issue(s): Foster Care and Residential Facilities; Incarcerated People

Special Populations

As with any population, the experiences of PwIDD and mental health difficulties vary from one person to the next. Intersectional identities often play a role in one's experiences and needs. The following section discusses diverse populations of PwIDD and co-occurring mental health difficulties and how their unique experiences may differ from others with IDD. It also enables the reader to look back to the framework topics for additional context.

Rural Communities

Summary: Most barriers to awareness, diagnosis, treatment, and quality of care identified in the general population of PwIDD are intensified for those living in rural areas. Data suggests a systematic relationship between impairment rates and geography highlighting higher rates of disability in rural areas. Of over 300 million Americans, roughly 37 million, or 12 %, report experiencing at least one type of impairment. In metropolitan counties, 11% of people reported having at least one of the six impairments associated with disability. In contrast, 15% of people living in micropolitan counties and 17% of people living in noncore counties reported at least one of the six impairments associated with disability (von Reichert et al., 2014). In addition, suicide rates in rural and micropolitan communities (urban areas with a population of at least 10,000 but fewer than 50,00) continue to exceed those in urban and suburban communities.

PwIDD living in rural areas tend to be more impacted by lack of awareness and visibility. Self-advocates, family/friends/allies, service providers and health care professionals in rural areas, in particular, lack the knowledge to recognize comorbid mental health conditions (Rural Health Information Hub, 2018). Purposeful silence around mental health conditions is compounded by the lack of privacy afforded in small towns, where self-advocates and/or families/friends/allies may fear the stigma associated with mental health conditions (Rural Health Information Hub, 2018).

Socioeconomic factors also compound mental health challenges in rural areas. For example, higher levels of poverty lead to more widespread financial distress and decreased levels of managed care. People in rural areas are also less likely to have any or adequate medical coverage for mental healthcare services (Rural Health Information Hub, 2018).

Access to quality mental health care providers is also more challenging in rural areas. It is challenging to recruit mental health care professionals to serve rural communities, due in part to low reimbursement rates, high no-show rates among mental health clients due in part to distance and transportation challenges, long-distance travel, social isolation, and high numbers of uninsured patients (Giuntoli et al., 2015; Rural Health Information Hub, 2018; Mental Health and Developmental Disabilities National Training Center, 2019). In addition, people often seek help during a crisis from hospitals, and rural hospitals are closing (Mental Health and Developmental Disabilities National Training Center, 2019). Integration of mental, behavioral, and primary healthcare can address this issue of provider access in rural areas. (Rural Health Information Hub, 2018).

Compounding limited access to mental health care providers, rural areas typically lack high-speed broadband internet services. This makes it challenging to use telehealth services (Mental Health and Developmental Disabilities National Training Center, 2019). One study found that patients receiving hybrid care including telepsychiatry and in-person visits experienced greater access to care compared to

patients receiving in-person care only. Patients were seen seven days sooner and were 34% more likely to have regular follow-up visits when combined with in-person care (Genoa Healthcare, 2019).

Audience(s): Self-Advocates; Families/Friends/Caregivers; Health Care Providers; Service Providers; Policymakers; IDD/BH/MH Agencies

Relevant Statistics:

- o In the United States, 4.8% of people report a cognitive disability and 19.1% of people in rural areas report a mental health condition. Of areas facing a shortage of health care providers, 61.5% are rural. There are fewer service providers in general as well as service providers who are trained to treat PwIDD and mental health conditions in rural areas (Mental Health and Developmental Disabilities National Training Center, 2019).
- o One in five Americans in rural areas lives with a mental health condition, yet 65% of non-metropolitan areas lack access to in-person psychiatric care.
- o Between 2004 and 2013, rural and micropolitan counties saw about a 20% increase in suicide. Large metropolitan counties saw a 7% increase over the same time period.
- o In 2013, the suicide rate in rural counties was 17.6 deaths per 100,000 compared with large central metropolitan counties at 10.3 deaths per 100,000 (Rural Health Information Hub, 2018).
- o A survey of state developmental disability and mental health directors conducted in the spring of 2003 revealed that key barriers to service provision included inadequate information on best practice (67%) and the shortage of qualified providers (78%; Moseley, 2004).
- o On the needs assessment survey of Texas self-advocates implemented for this project, 64% said they primarily receive mental health care remotely, demonstrating that self-advocates can successfully receive services via technology.

Remedies:

- o Rural areas need more service providers who are trained to treat PwIDD and mental health conditions (Mental Health and Developmental Disabilities National Training Center, 2019).
- o Access to telehealth to allow greater access to care must be combined with improved technology infrastructure and increasing reimbursement rates (Rural Health Information Hub, 2018; Genoa Healthcare, 2019; Mental Health and Developmental Disabilities National Training Center, 2019).
- o Stepped-care models focus on providing the most effective and least resource-intensive treatments first and only stepping up to more intensive or specialized treatments as the patient needs them. This approach could provide an effective model of treatment while utilizing the fewest resources (Mental Health and Developmental Disabilities National Training Center, 2019).
- o Successful triage and treatment of PwIDD in acute or routine settings must include staff training on environmental triggers (i.e., fluorescent lighting, overstimulating environments), effective diagnosis (e.g., distinguishing emergent from chronic issues), effective treatment models (i.e., RAFT—Respect, Accommodation, Follow-up, Time), and aspects of disability as they present in non-acute settings.

     o   Involving self-advocates from local Developmental Disabilities Council to assess current treatment settings and providing medical care staff opportunities to interact with PwIDD who are *not* in crisis can help them better serve PwIDD when they are in crisis (Pinals et al., 2017).

     Related Framework Topics

     o   Lack of Knowledge
     o   Stigma and Secrecy
     o   Lack of Technological Infrastructure
     o   Financial Incentives
     o   Recruitment of Mental Health Care Professionals
     o   Integration of Mental Healthcare and Primary Care
     o   Distance/Transportation
     o   Insurance Coverage:
     o   Provider Scarcity

Aging PwIDD

Summary: The life expectancy for PwIDD has grown from 19 years of age in 1930 to 66 years of age in 1993. Unlike most of the older adult population, aging PwIDD are more likely to be vulnerable to conditions that make growing older more difficult. For example, it is estimated that 50% of people with Down Syndrome will develop Alzheimer's as they age. Due to a history of low employment, PwIDD also have limited personal savings/income resulting in a greater need to rely on others. For many, their primary source of financial assistance, healthcare, and support is parents who are aging and in need of their own services and supports. Increased collaboration between agencies serving PwIDD, mental health conditions, and the aging can begin to address some of these care gaps (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Factors related to aging also impact the mental health of PwIDD. Many adult PwIDD have few opportunities to exercise self-determination to have a meaningful, fulfilling life. Increased self-determination across the lifespan can positively impact mental health in PwIDD (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019). In addition, the prevalence of major depression is higher in adult PwIDD compared with those without IDD. There is increasing evidence that mental health conditions, particularly affective and anxiety disorders, are associated with the experience of negative life events in adult PwIDD. Negative life events are also found to be predictive of later psychological trauma in PwIDD. Therefore, special care must be given to reduce the experience of negative life events by PwIDD as they age (Bond et al., 2019).

     Audience(s): Self-Advocates; Families/Friends/Caregivers; Health Care Providers; Service Providers; IDD/BH/MH Agencies

     Relevant Statistics:

     o   In Texas, there are more than 300,000 family caregivers, and only 7% of those families receive support from a state IDD agency. An estimated 70% of PwIDD live with family,

- and 20% of these family caregivers are age 60 or older (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).
  - o US data shows that 80–85% of children and adults with developmental disabilities will live with their families until their parents' health declines or they die (Utah Parent Center, 2013).
  - o Depression was reported by 84% of respondents to the needs assessment survey conducted with Texas self-advocates for this project.

Related Framework Topics:

- o Service Coordination
- o Systemic Barriers to Integrated Care
- o Unnecessary Institutionalizations

Racially- and Ethnically-Diverse PwIDD

Summary: Several studies indicate that racial/ethnic minority groups are disadvantaged in several essential areas of general and mental healthcare access and use. PwIDD who are members of marginalized racial and ethnic groups have a compounded risk of underutilization in terms of general care services (Scott & Havercamp, 2014). Black and Latinx children and those of low socioeconomic status with IDD and co-occurring mental health conditions are at a greater likelihood to be tracked into the juvenile justice system rather than the mental health system when mental healthcare is needed (Jacobstein et al., 2007).

These disparities may occur for a variety of reasons including

- limitations in/lack of health insurance coverage,
- lack of education in the medical field regarding care for PwIDD,
- communication/language barriers,
- difficulty with assessments, and
- compounded low socioeconomic status (Scott & Havercamp, 2014).

Innovative and aggressive new policy measures are urgently needed to address the health disparities among Black and Latinx PwIDD (Magana et al., 2016).

Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers; IDD/BH/MH Agencies; Policymakers

Relevant Statistics:

- o Compared to White adult PwIDD, Black adult PwIDD were 1.72 times more likely to be in fair or poor health, and 1.64 times more likely to be in fair or poor mental health. Latinx adults were 2.48 times more likely to be in fair or poor health and 2.2 times more likely to be in fair or poor mental health (Magana et al., 2016).
- o Latinx adult PwIDD were significantly more likely to be in fair and poor health and in fair or poor mental health than Latinx adults without IDD. Black adult PwIDD were significantly more likely to be in fair or poor health and fair or poor mental health than Black adults without IDD. (Magana et al., 2016).

Related Framework Topics:

- o Insensitive Diagnostic Approaches for Racially- and Ethnically-Diverse Populations
- o Culturally Competent Practitioners
- o Systemic Barriers to Integrated Care
- o Access to Care
- o Training
- o Recruitment of Mental Health Professionals

People with Autism Spectrum Disorder

Summary: Youth with autism spectrum disorder face barriers in accessing timely and appropriate mental health treatment, which places increasing demands on primary care providers to manage anxiety in youth with autism spectrum disorder (Vasa et al., 2016). Those with autism spectrum disorder may encounter delayed services and a lack of available care. Families were more likely to report a delay or nonreceipt of needed services when they perceived a lack of communication and partnership with their providers. A lack of sufficient insurance coverage and expensive out-of-pocket costs also contributed to the delay or non-receipt of services among those with autism spectrum disorder (Ahmedani & Hock, 2012).

Medication use is highly prevalent among those with autism spectrum disorder. Further research is needed to study the safety and efficacy of psychotropic intervention in adults with autism spectrum disorder (Buck et al., 2014). In addition, hospitalization rates are increased for those with autism spectrum disorder (Siegel et al., 2012). Health professionals working with children with autism spectrum disorder should give special attention to comorbid diagnoses during assessment and treatment planning, along with increased screening and referral to specialized treatment practices (Ahmedani & Hock, 2012).

Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers; IDD/BH/MH Agencies; Policymakers

Relevant Statistics:

- o Between 87% and 95% of children with autism spectrum disorder were also diagnosed with a comorbid psychiatric condition, including developmental delay, attention-deficit/hyperactivity disorder, anxiety problems, behavioral or conduct problems, and depression (Ahmedani & Hock, 2012).
- o Seventy-one percent of people with autism spectrum disorder studied were taking at least one medication, and 59% were taking psychotropic medication. Of those, 39% were taking at least two psychotropic medications, 26% were taking at least three, and 14% at least four. Meanwhile, 35% were taking anticonvulsant medications (Buck et al., 2014).
- o Children with an autism spectrum disorder utilized 11.9 times as many psychiatric hospital days as children without an autism spectrum disorder and incurred 12.4 times the cost (Siegel et al., 2012).

Related Framework Topics:

- o Appropriate Use of Medication
- o Comorbid Conditions
- o Fragmentation of Services
- o Insufficient Insurance Coverage
- o Integrated Care
- o Insensitive Diagnostic Approaches for Racially- and Ethnically-Diverse Populations
- o Lack of Specialized Hospital Units
- o Medication Inaccuracies
- o Poor Provider Communication
- o Service Coordination
- o Unnecessary Institutionalizations

People with Down Syndrome

Summary: PwIDD and Down Syndrome are at an increased risk for developing anxiety and depression. In addition, people with Down Syndrome are likely to develop Alzheimer's as they age, which compounds the need for mental health support (Hsieh et al., 2020).

Audience(s): Self-Advocates; Families/Friends/Caregivers; Health Care Providers; Service Providers

Related Framework Topics:

- o Caregiver Education
- o Lack of Knowledge
- o Comorbid Conditions
- o Aging PwIDD

Incarcerated PwIDD

Summary: PwIDD are more likely to be arrested, convicted, and sentenced to prison than nondisabled peers. Once in the criminal justice system, PwIDD are less likely to receive probation or parole and tend to serve longer sentences (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019). Concerns for PwIDD in the justice system include risks of victimization, failure to recognize their unique abilities and needs, denial of due process, and risks of discrimination in sentencing, release, and confinement. Additionally, PwIDD are at an increased risk of traumatization due to victimization, self-injury because of distress, and confinement in segregation units due to challenging behavior (Pinals et al, 2017).

Audience(s): Self-Advocates; Service Providers; Policymakers; IDD/BH/MH Agencies

Relevant Statistics:

- o PwIDD may represent 4-10% of the population, but among prison and jail inmates, cognitive disabilities are the most commonly reported disability—20% in prisons and 30% in jails (Pinals et al., 2017; Texas Council for Developmental Disabilities, n.d.).

- o Jail detainees are wait-listed to attend competence-to-stand-trial restoration programs. It is labor and cost intensive to treat PwIDD who have mental health issues as it can take years to complete a program that might only take months for someone with singular mental health issues. Additionally, placement may not be appropriate for PwIDD who do not require hospital-level care or who fare worse in a hospital setting (Pinals et al., 2017).
- o Under Texas law, jail personnel must notify the court within 72 hours of receiving credible information that a defendant may have an intellectual disability. However, due to lack of training and experience with intellectual disability, criminal justice and court personnel are often unable to quickly identify that a person may have an intellectual disability (Texas Council for Developmental Disabilities, n.d.).
- o 32% of children in the juvenile justice system have IDD, and 45% met criteria for emotional disturbance. Some studies estimate incarcerated youth with MHI is as high as 50-70% (Jacobstein et al., 2007).

Remedies:

- o State mental health agencies (SMHAs) should partner with IDD agencies overseeing services for this population. Outreach and collaboration with law enforcement, courts, and corrections to provide training on de-escalation, diversion approaches, cross-discipline education, and linkages to services and guidance in developing greater supports to accommodate persons with disabilities in justice and forensic systems. Programs should also develop alternatives to incarceration (Pinals et al., 2017).
- o Those entering the criminal justice system should receive a thorough screening and assessment by competent staff trained to identify mental health conditions, behavioral disorders, developmental disabilities, and substance use disorders (National Association of State Mental Health Program Directors, 2004).
- o SMHAs should partner in cross-agency activities and policy development to strengthen appropriate services for PwIDD within corrections and offer strategies to improve conditions of confinement targeting incarcerated PwIDD's needs (Pinals et al., 2017).
- o Advocacy groups have developed strategies for system reform and attention to unique needs of PwIDD, which should be incorporated in creating system reform. One recommended resource is the online publication *Impact* (Pinals et al., 2017).

Related Framework Topics:

- o Insensitive Diagnostic Approaches for Racially- and Ethnically-Diverse Populations
- o Lack of Trauma-Informed Care
- o Inappropriate Placement in Foster Care and Residential Facilities

Special Issues

The following section explores other issues that may be faced by PwIDD and mental health conditions and their families/caregivers. Additional presentations, stressors, and unique treatment settings are discussed. These topics include potential challenges and further needs of people experiencing such difficulties or receiving treatment in such settings.

Family/Caregiver Stressors

Summary: Those who care for children, youth, and adult PwIDD and co-occurring mental health conditions also have needs that are often ignored. For example:

- Having significant financial burdens
- Moving to different communities to find services for their loved one
- Being isolated and marginalized from family and community
- Having their own physical and mental health problems related to the stresses of constant care
- Feeling excluded and blamed by professional providers and find their views and opinions are ignored
- Feeling frustrated and exhausted when trying to access uncoordinated services
- Having inconsistent access to respite care and to their own support services
- Experiencing crises related to behavior or "meltdowns," which can be especially challenging when children grow larger than their parents (Utah Parent Center, 2013)
- Lacking the knowledge to recognize mental health condition or to distinguish symptoms of mental health conditions from those of IDD (Giuntoli et al., 2015; Putnam, 2009; Rural Health Information Hub, 2018; Hsieh et al., 2020)

Because most PwIDD and mental health conditions (90-95%) do not present for mental health services, caregiving is often left to families and others (Costello & Bouras, 2006). This makes addressing the needs of families and caregivers especially critical. The services and supports must be flexible to ensure that caregivers receive the specific help they need (Utah Parent Center, 2013).

> Audience(s): Family/Friends/Allies; Service Providers; Health Care Providers; IDD/BH/MH Agencies

> Relevant Statistics:

> - 80–85% of children and adults with developmental disabilities within the US will live with their families until their parents' health declines or they die (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).
> - 77% of adults with developmental disabilities are presently living with parents who are 60 or over. These family members spend between 50 and 60 hours per week on caring for their disabled child/adult by caregivers. Most of these caregivers are mothers (Utah Parent Center, 2013).
> - The prevalence of challenging behaviors among children and adults with developmental disabilities leads to increased stress in family caregivers. It also places the child or adult at greater risk of abuse, neglect, and deprivation (Utah Parent Center, 2013).

- o Of the Texas self-advocates reporting they currently receive help for one or more mental health conditions on this project's needs assessment survey, 61% reported that their families were their primary source of support.

Remedies:

- o Agencies and organizations should provide *significant and supported* training to help family caregivers address various challenges related to comorbid conditions, including:
    - understanding the conditions;
    - enhancing their own quality of life, safety, and wellness;
    - navigating a complicated care system;
    - finding care providers, support groups, and respite care
- o Family caregivers should be included meaningfully in all activities related to planning, designing, and implementing policies and programs for PwIDD.
- o Meaningful day supports/programs for the person with IDD that enhance their lives and are close to home should be cultivated.
- o Community living policies that support the social integration of people with disabilities and create social networks that make it easier for them to find help with daily or occasional needs should be prioritized
- o Family-driven systems of care and/or a medical home model should be cultivated.

Related Framework Topics:

- o Financial Relief
- o State Medicaid Agency Incentives
- o Financial Distress
- o Waitlists
- o Insufficient Insurance Coverage
- o Service Coordination
- o Fragmentation of Services
- o Integrated Care

Covid-19

Summary: As this framework was developed, baseline research emerged on the magnifying effect the Covid-19 global health emergency had on the mental health of PwIDD. While this research is preliminary and evolving, it must be emphasized that as significant and complex the issue of co-occurring IDD and mental health is, and as underserved as PwIDD and their caregivers are in all areas of mental health, Covid-19 has heightened the crisis further (APA 2020). This section summarizes the current impacts seen on PwIDD and their caregivers and the proposed remedies. However, it should be noted that long-term impacts are only now emerging and more study is needed.

Specific impacts on PwIDD include the following.

- Higher rates of overall stress due to increased isolation and loneliness (which has also been correlated to negative physical health effects) (APA 2020).

- Stress associated with not understanding the health measures required to keep themselves and others safe (Courtenay and Perera 2020, Tromans, et al 2020).
- Stress associated with changes in routine or changes in care staff (Courtenay and Perera 2020, Tromans, et al 2020).
- Increase in obsessive thinking which may escalate to paranoia (Courtenay and Perera 2020).
- Increased likelihood of regression in behavior and onset of challenging behavior (Tromans, et al 2020).
- Increased vulnerability to exploitation and abuse (Courtenay and Perera 2020).
- Mis-identification of mental health conditions as aspects of the person's disability (diagnostic overshadowing) (Tromans, et al 2020).
- Specific discrimination in accessing healthcare as it is "rationed" in times of crisis (APA 2020, Tromans, et al 2020).
- Over- or inappropriate medication (Tromans, et al 2020).
- Poor communication with health care professionals resulting from lack of in-person time (Tromans, et al 2020).

Impacts on those who care for PwIDD without pay (such as families/friends/allies) include the following.

- Significantly higher risk for depression and anxiety (Grumi, et al 2021, Tromans, et al 2020).
- Stress associated with the responsibility for ensuring the person they care for implements the safety measures required to keep themselves and others safe (Courtenay and Perera 2020).
- Worry about the PwIDD's future development given the lack of access to typically-available professional support (e.g., in schools, at care facilities, in home) and feeling that the caregiver is not equipped to meet the PwIDD's needs (Grumi, et al 2021).
- More use of maladaptive coping strategies than caregivers of people without disabilities (Willner, et al 2020).
- Significantly less social support than in pre-pandemic times, despite social support being a critical strategy to mitigate caregiver stress (Willner, et al 2021).

These stressors can work together to create undesirable and sometimes dangerous chains of events. For example, challenging behavior resulting from increased stress might render a caregiver unable to cope with the behavior, which in turn might lead to changes in placement, inappropriate medication, etc., (Courtenay and Perera 2020, Tromans, et al 2020).

All of the sources analyzed agree that more research needs to be done on the short- and long-term impacts of Covid-19. Such research should address the impacts and mitigation strategies for both PwIDD and their caregivers. It should emphasize the priorities of PwIDD (not the priorities of policymakers, organizations, or governments) (APA 2020, Grumi, et al 2021, Courtenay and Perera 2020, Tromans, et al 2020). In addition, the following recommendations were made:

- Greater, more organized support for families in the absence of the paid services they were used to receiving need to be planned for and provided by agencies and organizations currently serving PwIDD (Courtenay and Perera 2020, Grumi, et al 2021, Tromans, et al 2020, Willner, et al 2021).

- Immediate and significant professional mental health services for caregivers—above what is provided within the context of disability services—must be provided to ensure their recovery and continued ability to care for PwIDD (Willner, et al 2021).
- Places where PwIDD typically receive care need to rethink and fortify the services they provide in anticipation of a similar crisis, including emphasizing continuity of care and providing respite services for caregivers (Courtenay and Perera 2020, Tromans, et al 2020, Willner, et al 2021).
- Advance care planning for people with a high mortality risk needs to take place (Courtenay and Perera 2020).
- Policy needs to anticipate and address discrimination in care, which is heightened when care resources are scarce (Tromans, et al 2020). In addition, PwIDD and those that care for them need to learn about their rights in terms of access to health care during a public health emergency (APA 2020).
- Existing safeguarding measures need to be rethought as limited personal contact can lead to increased exploitation/abuse of PwIDD (Courtenay and Perera 2020, Tromans, et al 2020).
- Medication should be a last resort after exhausting all other appropriate responses to/treatments for behavior that may be based on mental health issues heightened by Covid-19 restrictions (Tromans, et al 2020).
- Because remote care has been the norm during pandemic lockdown, providers need to adapt their communication styles to be more appropriate for remote contact (e.g., slowing down speech, asking more questions) (Tromans, et al 2020).
- PwIDD need training and support to use technology to access care and to decrease feelings of social isolation. It may also be beneficial to create and study the use of online communities that enable PwIDD to communicate remotely with each other (Tromans, et al 2020, Willner, et al 2021).
- Governments need to provide sustainability grants to organizations serving PwIDD, as these individuals and their families tend to be in more financial distress and have greater need (Tromans, et al 2020).

Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers; IDD/BH/MH Agencies; Policymakers

Relevant Statistics:

In a study of caregivers of children with IDD conducted during the height of the pandemic (Willner, et al 2021):
- Forty-three percent reported high levels of anxiety compared to 8% of caregivers of children without disabilities.
- Forty-five percent reported major depression compared to 11% of caregivers of children without disabilities.
- Differences found between the two groups were 2-3 times greater than the differences found between the two groups in similar pre-pandemic studies.

In the needs assessment survey conducted as part of this project with Texas self-advocates during the pandemic:

- o Eighty-four percent of respondents reported having been diagnosed with depression.
- o Forty-nine percent of respondents reporting having been diagnosed with anxiety.

Related Framework Topics:

- o Caregiver Education
- o Financial Distress
- o Lack of Technological Infrastructure
- o Service Coordination
- o Co-Occurring Conditions
- o Disability-Insensitive Diagnostic Approaches
- o Telehealth
- o Over or Inappropriate Medication
- o Family/Caregiver Stressors

Trauma and PTSD

Summary: People with disabilities are over four times as likely to be victims of crime as people without disabilities (Charlton et al., 2004; Focht-New et al., 2008). Additionally, if a person has experienced one kind of abuse, it is likely that they have experienced other types of abuse as well (Bedard, 2013). Factors that contribute to this increased risk include a lack of education around social norms, healthy relationships, and sexual development, and being more dependent on support/services.

Children with lower intelligence quotient (IQ) are more susceptible to traumatic experiences, while youth with an IQ score greater than 115 at age 6 years were at a far lower risk for PTSD. (Breslau et al., 2005). PwIDD may experience cognitive and processing delays that interfere with understanding what is happening in abusive situations, produce feelings of isolation and withdrawal, and may make them more vulnerable to manipulation (Charlton et al., 2004; Lowe et al., 2007). Children exposed to abuse can experience negative social, emotional, behavioral, and academic outcomes (Dababnah et al., 2018).

Negative life events are associated with mental health conditions in PwIDD. However, most incidents of abuse and neglect of PwIDD are not reported. (Hove & Havik, 2010). A variety of factors interfere with the ability to report, such as difficulty communicating that abuse took place and not being believed when it is communicated (Pinals et al., 2017; Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

To address a history of victimization, studies have recommended the use of a biographical timeline as an assessment and intervention strategy, the use of a social therapeutic environment, supportive interventions, communication, and psychiatric care and therapy (Marcal & Trifoso, 2017; Focht-New et al., 2008; Focht-New et al., 2008). Psychopharmacology is recommended in the treatment of reexperiencing phenomena, avoidance and numbing phenomena, and hyperarousal (Focht-New et al., 2008).

Audience(s): Self-Advocates; Family/Friends/Allies; Service Providers; Health Care Providers; IDD/BH/MH Agencies

Relevant Statistics:

- o The rate of physical abuse among children with disabilities (per 1000) is 9.4, sexual abuse is 3.5, and emotional abuse is 3.5. In comparison, the rate of physical abuse among children without disabilities (per 1000) is 4.5, sexual abuse is 2.0, and emotional abuse is 2.9. (Charlton et al., 2004).
- o Five million crimes are committed against people with disabilities each year in the United States (Charlton et al., 2004).
- o People with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities. Maltreatment of children with disabilities is 1.5-to-10 times higher than of children without disabilities. One out of 30 cases of sexual abuse or assault of PwIDD is reported as opposed to one of five among people without a disability. (Charlton et al., 2004)
- o Even when abuse is reported, charges are rarely investigated when the victim has a disability. Victims typically have difficulty accessing appropriate services. Risk of abuse increases by 78% due to exposure to the disabilities service system alone (Charlton et al., 2004).
- o Immediate family members perpetrate most of the neglect, physical abuse, and emotional abuse, and extra-familial perpetrators account for the majority of sexual abuse. Sexual abuse incidents are almost four times as common in institutional settings as in the community. 99% of those who commit abuse are well known to, and trusted by, both the child and the child's care providers (Charlton et al., 2004).
- o A review of 50 studies revealed that sufficient evidence exists that children and youth with disabilities are at increased risk to be victims of violence. This effect was consistent across studies conducted in medical, child protective, law enforcement, and school settings, and the effects are cross-cultural. Reports of being forced to have sexual intercourse were about twice as high (19.6% vs. 9.4%) among girls with a physical or long-term health problem than among a group consisting of girls without such disabilities or health problems (Marcal & Trifoso, 2017).
- o According to various studies, PwIDD are anywhere from 3 to 10 times more likely to experience physical abuse, neglect, and/or sexual abuse in their lifetime (Bedard, 2013; Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Related Framework Topics:

- o Stigma and Secrecy
- o Assessment Tools
- o Multi-Dimensional Assessment Process
- o Comorbid Conditions
- o Appropriate Use of Medication
- o Psychotherapy
- o The Restorative Integral Support (RIS) model
- o Crisis Behavior Intervention Services
- o Medication Inaccuracies
- o Lack of Trauma-Informed Care
- o Unnecessary Institutionalizations
- o Integrated Care

- o Multi-Disciplinary Training
- o Person-Centered Care
- o Autonomy
- o Negative Attitude of Health Care Providers

Treatment in a School Setting

Summary: Special education services in the school setting must be equipped to work with children and adolescents with IDD who are also experiencing mental health difficulties. A unique Individualized Education Plan should be in place for children and adolescents with IDD and neurodevelopmental disorders that addresses both mental health issues and IDD (Pinals et al., 2017).

Audience(s): Health Care Providers; Family/Friends/Allies; Service Providers; Policymakers

Relevant Statistics:

- o The total number of students between the ages of 3 and 21 receiving special education services in Texas in the 2017-2018 school year was 498,588. Of these students, 54,134 were identified as intellectually disabled, 66,774 were identified as having autism spectrum disorder, and 7,163 were identified as multiply disabled (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).
- o A national report released in 2018 revealed while only 12% of students are students with disabilities, students with disabilities represented:
  - 28% of referrals to law enforcement or subjected to school-related events
  - 51% of students subjected to harassment or bullying based on their disability
  - 71% of all students restrained
  - 66% of all students secluded
  - 25% disciplined for bullying
  - 26% out of school suspensions
  - 24% expulsions (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019)
- o A review of public schools in Omaha, Nebraska, revealed that children with disabilities were more likely to be maltreated than peers without disabilities by the following multipliers: neglect: 3.76, physical abuse: 3.79, and sexual abuse: 3.14 (Marcal & Trifoso, 2017).
- o A clinical sample of 156 children with autism spectrum disorder revealed that 18.5% had been physically abused and 16.6% had been sexually abused. (Marcal & Trifoso, 2017).

Related Framework Topics:

Systemic Barriers to Integrated Care

Foster Care and Residential Facilities

Summary: According to the American Academy of Pediatrics Council on Children with Disabilities, children with IDD are at higher risk for out-of-home placement than other children and are at a particularly higher risk for placement in residential facilities (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019; Lowe et al., 2007; National Association of State

Mental Health Program Directors, 2015; Jacobstein et al., 2007). Being raised in large congregate settings with non-parental care by rotating shifts of caregivers results in poorer developmental outcomes compared to children raised in families. (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).

Audience(s): Self-Advocates; Service Providers; Health Care Providers; IDD/BH/MH Agencies; Policymakers

Relevant Statistics:

- o Primary reasons youth with disabilities to enter the foster care system are:
  - The child's behavior (21.2% for children with disabilities vs. 9.4% for children without) (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).
  - Parental inability to cope (22.9% for children with disabilities vs. 16.9% for children without)
  - Neglect (58.1% for children with disabilities vs. 60.1% for children without)
- o Youth with disabilities have been found to be more likely to experience placement instability and less likely to be reunified with family. These children are 2.47 times more likely than children without disabilities to live in a child welfare funded institution, and 2.2 times more likely than children without disabilities to live in a community-based group home (Texas Health and Human Services Statewide Behavioral Health Coordinating Council, 2019).
- o One study found that children with substantiated maltreatment who had disabilities were about twice as likely to be in out of home placement as children with substantiated maltreatment without disabilities. Being in out of home placement increases the chances of further maltreatment (Marcal & Trifoso, 2017).

Related Framework Topics:

- o Inappropriate Placement in Foster Care and Residential Facilities
- o Insensitive Diagnostic Approaches for Racially- and Ethnically-Diverse Populations
- o Culturally Competent Practitioners
- o Systemic Barriers to Integrated Care

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