



Hogg Foundation for Mental Health

THE UNIVERSITY OF TEXAS AT AUSTIN

Policy Recommendations: Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities (IDD)

It has been estimated that the rate of mental health conditions for those with IDD is two to three times higher than for the general population. Research findings have varied widely with prevalence rates for co-morbidity of IDD and mental health conditions ranging from 13.9% to 75.2%.² The variation in prevalence rates is likely due to lack of consistency regarding diagnostic definitions and assessment instruments, small sample sizes, lack of studies using non-IDD comparison groups and overuse of administrative samples (v. population samples), level of disability (IQ) and type of disability.³ For individuals with autism spectrum disorder (ASD) the numbers appear to be more defined with a 2011 study of 4,343 children with ASD finding the psychiatric co-morbidity rate by age 16 to be 49%.⁴

Depression and anxiety seem to be two of the most frequently identified mental health conditions in people with IDD but are certainly not the only ones.⁵ Research has also indicated an over-representation of schizophrenia in people with IDD compared to the general population.⁶ Post-traumatic stress has also been identified as a significant cause of mental health concerns in people with IDD.

Unfortunately, treatment practices have yet to catch up with the reality that people with IDD live with serious mental health conditions. Too many systems of care for people with IDD continue to focus on controlling and managing challenging behaviors without adequate consideration of the potential for underlying mental health or medical conditions as the cause of the behavior. The focus of treatment has historically been developing behavior management plans to promote compliance or the use of medications to control the behaviors. In both cases the treatment is targeting the behavior and not the actual mental health or medical condition making recovery unlikely.

Research in co-occurring IDD and mental illness in the US has been limited and lags behind Canada, Australia and Great Britain. Much of the research that has been done in the U.S. has been directed at the genetic aspects of the condition, looking primarily at specific disabilities and their link to certain mental illnesses. There have been a number of studies regarding autism spectrum disorder and mental health, but only some of these included individuals with IDD even though the comorbidity rate of autism and IDD is high.⁷

Often, the first line of “treatment” is psychopharmacological, with psychotropic drugs frequently being used to control the behavior rather than addressing a potential mental health condition. Consequently, standard psychosocial, behavioral and cognitive behavioral treatments have not been comprehensively studied even though there is strong evidence that

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“many individuals gain benefit from these interventions.”⁸ When individuals don’t receive appropriate treatment for mental illness, crises can occur. Even when appropriate services are available, crises can develop. Consequently, it is important to look at the spectrum of mental health services that are needed by people with IDD. We need to do all we can to prevent individuals from reaching the crisis stage, but we also must be prepared to support individuals and families when they do.

There are a number of challenges that have limited our progress in addressing the mental health needs of people with IDD. The challenges, however, should not deter our determination to fix the problems.

Challenges

1. **Overshadowing** – Providers and caregivers often attribute challenging behaviors to the disability and fail to adequately evaluate for underlying medical or mental health conditions. This often leads to “behavior interventions” that fail to address the reason for the behaviors. One study conducted in Great Britain concluded that:

People with ID (intellectual disabilities) are more likely to have significant health needs that may go unrecognized and untreated because of communication difficulties, diagnostic overshadowing, discrimination or indifference (Cumella and Martin, 2004; Disability Rights Commission, 2006; Health Care Commission, 2007; Michael, 2008).⁹

2. **Communication deficits** – Differences in communication can make it more difficult to assess, diagnose and treat both medical and mental health conditions in people with IDD. Additional time is often required to more adequately understand what the individual is experiencing. Expanded time is often required to accommodate the individual’s optimal mode of communication. Additionally, extended interviews with family and caregivers may be required to obtain information needed for assessment.
3. **Significant workforce shortage of MH/IDD professional expertise** – Texas has a significant shortage of all types of mental health professionals. As of November 2013, the federal government designated 207 of the 254 Texas counties as Mental Health Professional Shortage Areas for Mental Health.¹⁰ Within the mental health workforce there is limited expertise in working with people with IDD. Additionally, many in the IDD workforce have very limited knowledge and training in mental health. A 2012 study published in the *British Journal of Medicine* revealed that most general practitioners rely on experience-based knowledge as treatment of patients with IDD and behavioral or mental health conditions is rarely taught in medical school and is infrequently the focus of medical papers.¹¹
4. **Lack of cross agency/department coordination** – DSHS has little knowledge/experience working with people with IDD and DADS has limited expertise in the mental health needs of people with IDD. Although the local mental health centers and the local authorities (for IDD services) are typically co-located, service coordination and provision are siloed making it difficult for individuals with IDD to access mental health services.
5. **Few US studies on prevalence** – Only limited data is collected on those dually diagnosed with IDD and mental health conditions, making it difficult to identify more precisely what is needed and where it is needed. Texas is not alone, as overall US research on IDD/MH has been limited.
6. **Presence of challenging behaviors does not aid in identifying specific mental health conditions** – Behavior has been shown to be a means of communicating distress, not a diagnostic characteristic. A 2012 study suggests that for individuals with limited communication skills, there are few ways to convey the pain or distress they are experiencing or to convey their frustration with their environment or aversive management techniques being used.¹²

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- 7. Number of symptoms required to make a diagnosis may be too high for people with IDD** – Due to difficulty in assessment and communication, meeting the standard criteria for mental illness may be difficult. Lower levels of cognitive functioning can create significant challenges in diagnosis. Individuals may fail to meet the criteria because of inability to express what they are experiencing or feeling. Individuals with IDD may have difficulty in self-reporting their internal state.
- 8. Perception that aggression and irritability can be treated effectively with drugs** – This can discourage the need for a comprehensive evaluation.¹³
- 9. Appropriate assessment tools** – The assessment tool used can impact the accuracy of the diagnosis.¹⁴ Current diagnostic criteria may need to be modified for this population.¹⁵
- 10. People with IDD and ASD are often treated with psychotropic and other pharmacological drugs for their behaviors rather than for diagnosed psychiatric conditions.**¹⁶ – Many individuals are often prescribed multiple medications. One study of over 60,000 children with ASD across the country showed that between 2001 – 2005, 56% of the children studied had used at least one psychotropic medication with 20% receiving three or more.¹⁷ Researchers Esbensen and colleagues believe that the trend of medicating the ASD population is increasing even though there are concerns that the data does not support this practice.¹⁸
- 11. Lack of consideration to adverse events (trauma) in the lives of individuals with IDD and the impact on behaviors**¹⁹ – Significant attention has been given to the importance of recognizing the impact of trauma and the need for trauma-informed care for children in the child welfare and juvenile justice systems. The legislature has mandated certain levels of trauma training in both these systems. In spite of the fact that the individuals with IDD experience high rates of abuse, neglect, bullying and institutionalization, Texas has not yet recognized the importance of prioritizing trauma-informed care for this population.
- 12. Lack of prevention, intervention and crisis services and supports at the local and state level** – Some programs have identified the mental health and behavior crisis support needs of individuals with IDD and are beginning to build more appropriate systems of support. Many, however, continue to rely on behavior management practices and the use of pharmacological interventions to control behavior which often leaves the underlying issues unaddressed.
- 13. Lack of inclusion of people with IDD in state mental health policy** – Each agency sets their strategic priorities – DSHS for addressing the mental health needs of Texans and DADS addressing the needs of people with disabilities. More effort needs to be given to capitalizing on the expertise in both agencies to better serve the support needs of people with co-occurring IDD and mental health conditions.

Strategies

- 1. Recovery** – Develop a recovery focused approach to care for people with co-occurring IDD and mental health conditions. We know that people living with mental illness can recover. The Substance Abuse and Mental Health Services Administration (SAMSHA) defines recovery as “A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.”²⁰ The mental health system in Texas is a recovery-based system. However, the principles of recovery have not been incorporated into our system of care for people with IDD.

Since being identified as the most important aim of behavioral health services by both the 1999 Surgeon General’s Report on Mental Health and the 2003 President’s New Freedom Commission, the notion of recovery has rapidly and broadly permeated the American behavioral health system. (SAMHSA)

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2. **Cross-agency collaboration** – DSHS and DADS must work more closely to identify the mental health needs of those with IDD and take joint responsibility for meeting those needs.
 - a. **Create a cross-agency mental health unit/division for people with IDD. This division should build capacity for high quality standards, prevention, treatment and crisis support and services including crisis intervention teams.**
 - b. Recognize that substantial improvement is needed.
 - c. Prioritize the development of expertise and capacity across agencies.
 - d. Promote the use of non-pharmacological treatment – psycho-social, behavioral, and cognitive therapies.
 - e. Increase expectations that people with IDD will receive quality mental health services by developing standards of care in policies and practices that are recovery-based.
 - f. Develop a guide for providers and caregivers to provide a framework to improve access to quality mental health services for people with IDD
3. **Increase workforce capacity through training and ongoing consultation** – In a study published in 2006 in the Journal of Intellectual Disability Research, “psychiatrists expressed concerns about treatment of this group, describing unmet needs. A total of 75% considered that antipsychotics were overused to control aggression, and 34% of psychiatrists were reluctant to treat adults with an ID. In total, 85% agreed that mental health in ID should be offered as a training option for psychiatric residents, and that specialized mental health services would provide a high standard of care for this population.”²¹
4. **Integrated care** – Develop systems of true integrated physical and behavioral health services for people with IDD. Include IDD population in state health and mental health strategic planning.
5. **DM-ID** – A companion manual to the DSM-IV, the DM-ID, was developed collaboratively by the American Psychiatric Association and NADD (National association for those with dual diagnosis of IDD and mental health conditions). This manual focuses on the diagnostic criteria for diagnosing mental health conditions for people with IDD.
 - a. Promote use of the DM-ID within the public and private systems of care.
 - b. Include training in post-secondary professional trainings.
6. **Underlying medical conditions** – Increase screening efforts to identify underlying medical issues that may be causing challenging behaviors.
7. **Non-pharmacological supports and services** – Experts have argued that non-pharmacological - approaches to addressing challenging behaviors offer safer options for some individuals with IDD. Texas should:
 - a. Ensure that non-pharmaceutical options for treatment are available.
 - b. Monitor use of psychotropic medications being prescribed to individuals with IDD in state community and institutional programs.
8. **Mental health and trauma-informed care training** – Staff at all levels of care provision should be trained to understand and identify potential mental health needs of the individuals they are supporting, A 2006 study published in the *Journal of Applied Research in Intellectual Disability* indicated that a majority of the staff involved in the study were not aware that mental health conditions often manifest in behavior challenges and approximately a quarter of the participants thought that intellectual disability was equivalent to mental health problems.²²

Require trauma-informed care training throughout the IDD system. The Hogg Foundation is completing a two-year trauma-informed care training and technical assistance project at two state supported living centers aimed at reducing the use of restraint to control behaviors. A recent evaluation of the project indicated that while “systems change often takes many years, and, while there are always areas to improve upon in any system, it is clear a concerted effort has been put forth at both centers resulting in positive changes towards becoming a trauma-informed system of care.” Additionally, staff at one of the facilities “overwhelmingly reported the incidence

of restraints had significantly lowered from where they were two years ago, noting things such as increase communication, empathy and new skills as reasons the rate of restraints had decreased.”²³

- 9. Positive Behavior Supports** – Using positive behavior support strategies can effectively help to prevent crises from occurring and support individuals and families when crises do occur. Positive behavior support is a set of research-based strategies used to improve quality of life and decrease challenging behaviors. While there are many components to a comprehensive PBS system, supports are provided by making changes to the individual’s environment and teaching new skills.

The Crisis Prevention and Intervention Subcommittee of the Interagency Task Force for Children with Special Needs recommended in their January 2014 report that “Texas establish a statewide network and delivery system of PBS to ensure that children with special needs and their families receive supports and services that prevent and reduce challenging behaviors and related crises.”²⁴

More information on positive behavior supports can be found in a policy research brief entitled, “So Far and Yet So Near: Policy Development for Positive Behavior Support,” developed by EveryChild, Inc. as part of a policy research project funded by the Hogg Foundation.²⁵

- 10. Promoting Independence** – Texas should continue “promoting independence” initiatives. Studies have shown reduced challenging behaviors and improved quality of life for individuals who have transitioned from institutions to community settings.²⁶

11. Crisis intervention programs

- a. **Crisis Response Teams** – Crisis response teams that currently exist to support individuals experiencing a mental health crisis should be trained to provide crisis intervention to people with intellectual disabilities. Additionally, specialized crisis teams should be developed in each region to provide direct emergency services to people with IDD and to support other city and county crisis response teams.
- b. **START** – Systemic, Therapeutic, Assessment, Respite and Treatment was initially developed at the University of Massachusetts in 1989. In 2011, START was identified by the National Association of Developmental Disability Directors as a national best practice.²⁷ START teams are created at the local level to coordinate systems and services to improve diagnosis accuracy, treatment outcomes and service delivery.²⁸ Services included in the START model include interdisciplinary clinical consultation teams, 24-hour emergency services, planned and emergency respite, and ongoing training to the system of care. A START model is being implemented at Austin Travis County Integral Care through an 1115 waiver project. Evaluations of the START program have indicated improved access to appropriate services, reduction in emergency service use, and improvements in the quality of community living.²⁹
- c. **Emergency respite facilities** – Currently, the only residential supports that exist for someone with IDD in crisis are hospitals, psychiatric hospitals or SSLCs – all of which are extremely costly. Making respite available to individuals in crisis allows opportunities for the individual, the family and the support team to stabilize, assess and develop a plan for recovery.
- d. **Wellness Recovery Action Plan (WRAP)** – As described on the WRAP website, “The Wellness Recovery Action Plan®, or WRAP®, is an **evidence-based system** that is used world-wide by people who are dealing with mental health challenges as well as medical conditions such as diabetes, weight gain and pain management, and life issues like addictions, smoking, and trauma.”³⁰ WRAP planning helps individuals identify what makes them well and uses self-identified tools to maintain wellness, often resulting in recovery and long term stability. The Copeland Center, where WRAP was developed recently released a WRAP workbook for adults who have developmental disabilities. It contains crisis and post-crisis plans and provides suggestions caregivers can use when assisting someone who may learn and/or communicate differently.

Key elements of WRAP®:

- Wellness Toolbox
- Daily Maintenance Plan
- Identifying Triggers and an Action Plan
- Identifying Early Warning Signs and an Action Plan
- Identifying When Things Are Breaking Down and an Action Plan
- Crisis Planning
- Post Crisis Planning.

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- 12. Australian National Roundtable on the Mental Health of People with Disabilities** – This gathering of national experts in 2013 identified key elements of an effective system of mental health care for people with intellectual disabilities. These include:
- a. The needs of people with an intellectual disabilities and a mental disorder are specifically accommodated in all mental health initiatives.
 - b. People with intellectual disability and their families receive education and support to prevent mental disorders and to obtain early and timely assistance for mental disorders.
 - c. All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disabilities.
 - d. A national network of specialists in intellectual disability and mental health is available to support mainstream mental health services – by provision of consultation and training, and through research.
 - e. Ongoing joint planning by disability services, schools and mental health and other relevant services including:
 - i. Identification of referral and treatment pathways
 - ii. Development of a framework and capacity for collaborative responses where intellectual disability and mental disorder co-exist.
 - f. Training in intellectual disability and mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.
 - g. Collection and analysis of data which measures mental health needs, access to services and outcomes of people with intellectual disability.
 - h. All of these elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drug misuse, indigenous status and contact with the criminal justice system.³¹

- 13. A guide for providers** – Develop a guide for providers modeled after *The Guide: Accessible Mental Health Services for People with an Intellectual Disability*, developed by the Department of Developmental Disability Neuropsychiatry at the University of South Wales in Sidney Australia.³²

The Center for Autism and Related Disabilities at the University of South Florida has also developed an informative guide entitled *Autism & Mental Health Issues: A guidebook on mental health issues affecting individuals with Autism Spectrum Disorder*.³³ This guide also provides an effective framework for building awareness and developing competencies relating to the mental health needs of people with IDD.

The Hogg Foundation has partnered with the National Child Traumatic Stress Network for the development of a toolkit and curriculum to be used to provide training for trauma-informed care for children with IDD. The project includes statewide trainings that will be conducted by SafePlace.

Summary

We must continue the conversation and continue to build awareness of the long ignored mental health needs of people with IDD. People living with intellectual and other developmental disabilities have the same human right to quality mental health services as everyone else. Historical paradigms have created default systems of care that attempt to manage behaviors without addressing the underlying causes. Higher quality, comprehensive mental health and medical assessments are the first step to identifying causes of challenging behaviors. Quality services, supports and treatments should follow. A focus on recovery will benefit the individual as well as providers and staff. Additionally, the cost of care for individuals in recovery is much lower than the high cost of institutionalization.

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