Serious Mental Illness Among Individuals with IDD

Definition & Diagnosis

Diagnosis of serious mental illness (SMI) requires adult patients to meet the following criteria:

- A mental, behavioral, or emotional disorder (excluding intellectual or developmental disabilities & substance use disorders)
- Currently diagnosable or diagnosable within the past year
- Illness meets diagnostic criteria specified in the 5th edition of the *Diagnostic & Statistical Manual of Mental Disorders*
- Results in serious functional impairment & substantially limits or interferes with daily activities (e.g., employment, social involvement, relationship maintenance, etc.)

Commonly diagnosed SMIs include:

- Major depression
- Schizophrenia
- Bipolar disorder
- Other mental disorders causing serious impairment

The cause of mental illness is not reducible to any lone factor, but rather is influenced by a constellation of biological & social factors, including genetic predisposition, intellectual or developmental abilities, physical health, environmental factors, traumatic events, social connections, family history, economic situation, & individual personality characteristics.

Sources: APA 2015; NADD 2015; NAMI 2015; NIMH 2015; SAMHSA 2015

Facts & Figures

People with cognitive disorders, known as intellectual & developmental disabilities (IDD), have significantly higher rates of mental illness & related problem behaviors when compared to the general population.

- Roughly 1.5-3.0% of people are diagnosed with an IDD, & of those, up to 35% have a co-occurring mental illness
- In 2012, approximately 9.6 million U.S. adults aged 18+ were living with a SMI, representing just over 4% of the general U.S. population
- Down Syndrome is associated with lower rates of mental illness & related problem behaviors than other IDD-related conditions, such as autism spectrum disorders (ASD)
- Early identification & intervention is key to preventing the development of SMI, as 50% of mental illnesses emerge by age 14, & 75% of mental illnesses manifest by age 24
- Overall, women are more likely than men to be diagnosed with SMI (4.9% & 3.2%, respectively)
- Asians, Hawaiian Natives, & Pacific Islanders are the least likely ethnicities to report SMI (2.0% & 1.8%, respectively)
- A 2008 analysis of 31 studies reveals that while people with SMI are somewhat more likely than the general population to perpetrate violence, they are far more likely to become victims of violence

Sources: Choe et al. 2008; Mantry et al. 2007; NADD 2015; NIMH 2015; Webb et al. 2010

Risk Factors

Some subpopulations, such as people diagnosed with IDD, face a greater risk of developing SMI. At-risk people generally have less access to care, disrupted service use, & poorer health outcomes, as documented among patients with IDD. Specialized medical & behavioral providers are especially important for patients with SMI who have co-occurring conditions, such as ASD or other forms of IDD, yet community-based heath care specialized for patients with IDD is rarely available. Health disparities among vulnerable populations may be caused by limited health clinics, a dearth of information about mental health care, the absence of culturally and/or linguistically diverse health providers, & the scarcity of specialized health care providers.

Groups at high risk for SMI include:

- People with ASD and/or IDD
- People with physical disabilities
- LGBTQ populations
- Transition-age youth
- Adults aged 26-49
- Native Americans/Alaskans & Latinos

Sources: Arc 2015; Bradford 2008; Burkett et al. 2015; Grinker et al. 2015; Melville et al. 2008; NIMH 2015; Robertson et al. 2015; Ryan et al. 2015; SAMHSA 2015;

Social Stigma

Research reveals that people with IDD are one of the most stigmatized groups, & that patients with SMI experience even greater social stigma than those with IDD. Social stigma often leads to negative stereotypes that devalue people with distinguishing characteristics, such as obvious developmental disorders or mental illnesses. Negative stereotypes frequently result in social isolation & discrimination in social institutions such as education, employment, & health care. Not only is social stigma a risk factor for mental illness, it is also a barrier faced by patients with when they contemplate seeking mental health care. Because of the lack of sensitivity toward people who are mentally ill, patients with IDD, who are already harshly stigmatized for their cognitive disabilities, may feel discouraged from procuring treatment until their mental illness has dangerously escalated. Patients with IDD & co-occurring SMI experience multiple layers of stigma, yet have less access than the general public to specialized resources that address their confounding ailments.

To prevent the escalation of SMI, particularly among at-risk populations, public awareness about the following items is vital:

- Prevalence of mental illness in the general population, & common warning signs or risk factors
- Holistic, community-based treatment options available to patients who are suffering from mental illness
- Support services available to families & caregivers of patients with SMI, especially for those of patients with co-occurring conditions, such as IDD
- Intervention/de-escalation tactics for employers & law enforcement who may be first-responders to behavioral or emotional SMI-related emergencies

Sources: AAID 2009; Arc 2015; Burkett et al. 2015; Grinker et al. 2015; NADD 2015; Oullette-Kuntz et al. 2010; Ryan et al. 2015; Scior et al. 2013; Starke 2011

Co-occurring Conditions

Co-occurring conditions are two or more illnesses experienced simultaneously. Common co-occurring conditions with SMI include IDD, substance abuse, cardiovascular issues, & diabetes. Symptoms of IDD-related conditions sometimes mask or are prioritized over mental health red flags, which can reduce the overall efficacy of treatment plans. Patients diagnosed with SMI & co-occurring conditions, such as IDD, should receive treatments that comprehensively address all components of their mental & physical health conditions. If left untreated, patients with SMI are more likely to experience early death or develop degenerative co-occurring chronic conditions.

Prompt medical attention to SMI & co-occurring conditions is important for the following reasons:

- 50% to 90% of people with SMI have one or more co-occurring chronic medical conditions
- A diagnosis of SMI is associated with death from 7 to 25 years earlier than for those without a SMI
- 90% of all people who die by suicide have a SMI
- 20-25% of homeless people report having a SMI
- Health costs for patients with both mental illness & chronic health issues are about 75% higher than patients without a mental illness

Sources: Dixon 1999; MHPA 2015; NADD 2015; SAMHSA 2015; Sterling et al. 2010; Viron 2012

Treatment: Medical, Psychological, Social

Patients with SMI & co-occurring IDD often need specialized treatment plans & additional support to regain their mental health. SMI is characterized by patients' difficulty managing daily responsibilities, such as strained relationships, job loss, & reduced ability to perform self care. Though SMI can be successfully combated via a three pronged approach (medical, psychological, social), SMI often involves episodes of illness & relapse, which requires patience & persistence from all parties involved in a treatment plan.

- Patients can become eligible for Medicaid because they are disabled by SMI, or they may be eligible because of other health issues, such as ASD or IDD, & simultaneously have a mental health condition
- While antipsychotic & mood stabilizing medications are useful components of SMI treatment, they may be associated with an elevated risk of sudden cardiac death, & other adverse reactions that make it difficult to socially engage, such as sedation, weight gain, & sexual dysfunction
- Successful treatment approaches to SMI involve both medical care & community based approaches that address psychosocial issues including relationships, housing, employment, & transportation
- Integration of mental & emotional health development into community health outreach can support the prevention of other public health issues, such as unplanned pregnancy, violence, tobacco use, & homelessness
- Due to a lack of robust research & provider training, medical & behavioral health interventions for people with ASD or IDD are generally not evidence-based & can produce unrealistic or discriminatory treatment plans

Sources: APA 2015; Arc 2015; Bellack et al. 2006; Burkett et al. 2015; Grinker et al. 2015; MHPA 2015; Melville et al. 2008; Muench et al. 2010; Ray et al. 2001; Robertson et al. 2015; Ryan et al. 2015; SAMHSA 2015

Overlap & Links Between SMI & IDD

Research on SMI demonstrates that at-risk populations, such as those with IDD or other disabilities, are more likely to have co-occurring conditions & barriers to specialized health care. While much of the recent research on SMI has focused on racial & economic disparities in mental health care, it is important to note that patients with IDD often face physical & social challenges (i.e., chronic illness, social exclusion, difficult developmental transitions) that are known contributors to the onset of SMI. Due to a lack of specialized IDD knowledge among health care providers, some patients with IDD may manifest SMI symptoms & related problem behaviors that are misattributed to common IDD symptoms.

A recent review of the top fifteen medical journals reveals that fewer than ten articles have been published about IDD among adults in the past fifteen years. This dearth of medical attention to IDD indicates that currently practicing health providers are largely unprepared to manage patients with IDD who may have several serious co-occurring conditions (IDD, SMI, & chronic/frequent physical illness). Because many patients with IDD are now living in independent or semi-independent settings, it is imperative that community health professionals be provided more extensive information about how to properly address the special health care needs of patients with IDD, especially mental wellness.

With focused training & support from medical specialists of IDD, community health care providers will be more prepared to identify patients with IDD who experience mental health crises. Patients with IDD require an SMI treatment plan that provides solutions on multiple levels (medical, psychological, social), coupled with family & caregiver support.

Bibliography

1. Bellack A, et al. 2006. A Randomized Clinical Trial of a New Behavioral Treatment for Drug Abuse in People with Severe and Persistent Mental Illness. *Archives of General Psychiatry* 63:426-432.
2. Bradford D, et al. 2008. Access to Medical Care among Persons With Psychotic and Major Affective Disorders. *Psychiatric Services* 59:847-852.
3. Burkett K, et al. 2015. African American Families on Autism Diagnosis and Treatment: The Influence of Culture. *Journal of Autism and Developmental Disorders* 1-11.
4. Choe J, et al. 2008. Perpetration of Violence, Violent Victimization, and Severe Mental Illness: Balancing Public Health Concerns. *Psychiatric Services* 59:153-164.
5. Dixon L. 1999. Dual Diagnosis of Substance Abuse in Schizophrenia: Prevalence and Impact on Outcomes. *Schizophrenia Research* 35:S93–S100.
6. Grinker R, et al. 2015. Cultural Adaptation and Translation of Outreach Materials on Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 45:2329-2336.
7. Mantry D, et al. 2007. The Prevalence and Incidence of Mental Ill-health in Adults with Down Syndrome. *Journal of Intellectual Disability Research* 52:141–155.
8. Muench J. 2010. Adverse Effects of Antipsychotic Medications. *American Family Physician* 81:617-22.
9. Ouellette-Kuntz H, et al. 2010. Public Attitudes towards Individuals with Intellectual Disabilities as Measured by the Concept of Social Distance. *Journal of Applied Research in Intellectual Disabilities* 23:132-142.
10. Ray W, et al. 2001. Antipsychotics and the Risk of Sudden Cardiac Death. *Archives of General Psychiatry* 58:1161-1167.
11. Robertson J, et al. 2015. Systematic Reviews of the Health or Health care of People with Intellectual Disabilities: A Systematic Review to Identify Gaps in the Evidence Base. *Journal of Applied Research in Intellectual Disabilities* 28:455-523.
12. Ryan T, et al. 2015. Medical Students' Attitudes Towards Health Care for People with Intellectual Disabilities: A Qualitative Study. *Journal of Applied Research in Intellectual Disabilities* doi:10.1111/jar.12206.
13. Scior K, et al. 2013. The Effects of Symptom Recognition and Diagnostic Labels on Public Beliefs, Emotional Reactions, and Stigmas Associated with Intellectual Disability. *American Journal on Intellectual and Developmental Disabilities* 118:211-223.
14. Starke M. 2011. Young Adults with Intellectual Disability Recall their Childhood. *Journal of Intellectual Disabilities* 15:229-240.
15. Sterling S, et al. 2010. Access to Treatment for Adolescents With Substance Use and Co-Occurring Disorders: Challenges and Opportunities. *Journal of the American Academy of Children & Adolescent Psychiatry* 49:637-646.
16. Viron M, et al. 2012. Schizophrenia for Primary Care Providers: How to Contribute to the Care of a Vulnerable Patient Population. *The American Journal of Medicine* 125:223-230.
17. Webb R, et al. 2010. Influence of Environmental Factors in Higher Risk of Sudden Infant Death Syndrome Linked With Parental Mental Illness. *Archives of General Psychiatry* 67:69-77.

Web Resources

- **American Association on Intellectual & Developmental Disabilities: www.aaidd.org**
- **American Psychological Association: www.apa.org**
- **DETECT Mississippi: www.detectms.com**
- **Medicaid Health Plans of America: www.mhpa.org**
- **National Alliance on Mental Illness: www.nami.org**
- **National Institute of Mental Health: www.nimh.nih.gov**
- **Substance Abuse & Mental Health Services Administration: www.samhsa.gov**
- **The National Association for the Dually Diagnosed: www.thenadd.org**
- **The Arc. For people with intellectual & developmental disabilities: www.thearc.org**

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