Is there a correlation between depression and medical conditions among people with IDD enrolled in START?
NC START West
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Systemic · Therapeutic · Assessment · Resources · Treatment

Introduction

There is considerable research that examines the relationship between depression and medical conditions. Most evidence shows that this relationship is complex and multifaceted, noting that physiological changes in the brain and body can play a significant role in depression developing secondary to a medical condition. Research indicates that the prevalence of depression is increased among people who experience chronic medical conditions such as epilepsy, high blood pressure, diabetes, and chronic pain compared to those who do not have such conditions.

START provides support for individuals who are diagnosed with an intellectual disability (ID) and/or autism spectrum disorder (ASD) and co-occurring mental health and/or behavioral challenges. START focuses on a biopsychosocial model where biological vulnerabilities are considered first when behavioral challenges are present. Given the multitude of medical conditions present in the people who experience neurodevelopmental disorders, the focus of this poster session is to examine the potential underdiagnosis of depression in people supported by START.

START gathers information at intake regarding medical, neurodevelopmental, and psychiatric diagnoses. Historic records are obtained to gain further insight into what happened in the past, including a comprehensive social history, and any previous diagnoses the person may have carried. Medical records are also obtained to help give a complete picture of the person. Many people supported by START are on a plethora of medications for anxiety, mood stabilization, and psychosis, but a small percent of people on medication for depression. Given the increased likelihood that medical needs are underreported for people who carry neurodevelopmental diagnoses, it is hypothesized that depression would be more prevalent based on the array of medical diagnoses seen in START participants, especially among those likely experiencing chronic pain or discomfort.

Literature Review

There is a vast body of research that explores the bi-directional relationship between depressive disorders and chronic medical conditions. It is clear from the research that people with chronic illnesses are significantly more likely to experience depression than the general population. One 2017 study found that 27% of people with diabetes, 42% of people with cancer, and 43% of people with obesity experience depression and many other medical conditions correlated with increased prevalence of depression as well (Geng & Taft, 2021). Notably less research exists exploring the prevalence of these comorbidities among the population of people with intellectual disabilities (ID).

The relationship between depression and many chronic medical conditions creates a compounding effect in which the discomfort, physical limitations, or feelings of discouragement caused by the medical disorder serve to prevent the person from actively addressing their depression, worsening their mental health and further reducing the likelihood that they will properly address their physical condition as well (NIH publication No.24-MH-8015).

Many chronic illnesses negatively impact a person's ability to engage in exercise or leisure activities, work, personal relationships (especially if help with personal care is required), and correlate with worsened self-image and reduced hope for the future. Comorbid medical conditions are linked to increased severity and duration of depressive episodes and reduced capacity to recover from these episodes (Patten, 2004). Socioeconomic status and the burden of participating in and paying for medical and mental health treatment also plays a role in worsened depression among people with comorbid medical conditions (Wong, Mercer, Woo, & Leung, 2008).

There is a reliance of self-report of symptoms when diagnosing and treating medical conditions and depression. The population of people with ID (especially people with moderate-severe ID) struggle with reduced capacity to describe their symptoms. Also, caregivers as well as professionals often misunderstand the symptoms. Treatment challenges include the reliance on high levels of verbal processing that are difficult for many individual with ID. Additionally, the widespread lack of full participation in social activities, meaningful employment, and other positive protective factors indicates that this population is likely at significantly greater risk for depression compared to the population of people who do not have ID. In fact, the additional risk factors such as challenges with self-report and challenges engaging in treatment and social relationships should mean that people with more limiting intellectual disabilities would be at greater risk for depression and comorbid medical conditions, than those without an ID and those with a mild ID, but both conditions may be under-diagnosed. Maiano et.al (2018) found that prevalence of depression among children and youth was higher among children with ID, but mostly only among the borderline-mild ID range. Prevalence decreased once examining the moderate-severe ID range, and the author hypothesized that this was due to challenges with diagnosis that are related to communication difficulties experienced by this population.

References

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Methodology

Selected data from the SIRS (START Information Reporting System) database, was used to determine the prevalence of medical conditions known to be associated with depression to be cross-referenced with the data denoting a depressive disorder and compared to the general population. Medical conditions considered to be pain related were gastrointestinal disorders, genitourinary disorders, musculoskeletal disorders, cerebral palsy, dental/oral conditions, and obesity.

130 START participants enrolled during 2024 were used in this sample. Two sets of data were considered: people with a depressive disorder diagnosis and co-occurring medical diagnoses that often lead to pain and people without a depressive disorder and medical diagnoses that often lead to pain. Levels of ID were considered to determine the number of people who may not be able to accurately report discomfort associated with an undiagnosed medical condition. The group was also sorted by numbers of comorbid medical conditions to examine if any shift in prevalence of depression was observed based on medical experience and level of ID.

Findings

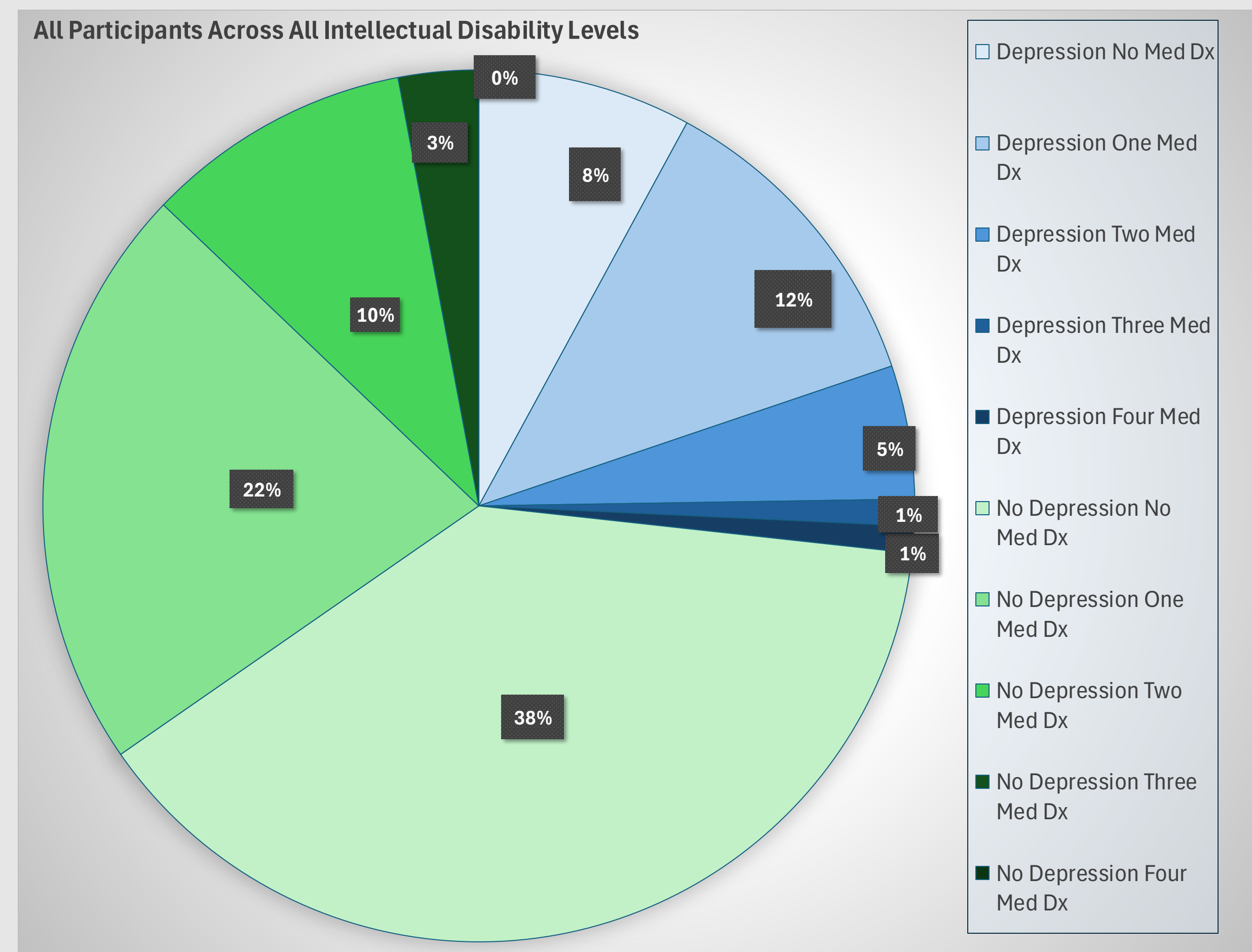Depressive Diagnosis / No Depressive Diagnosis charts
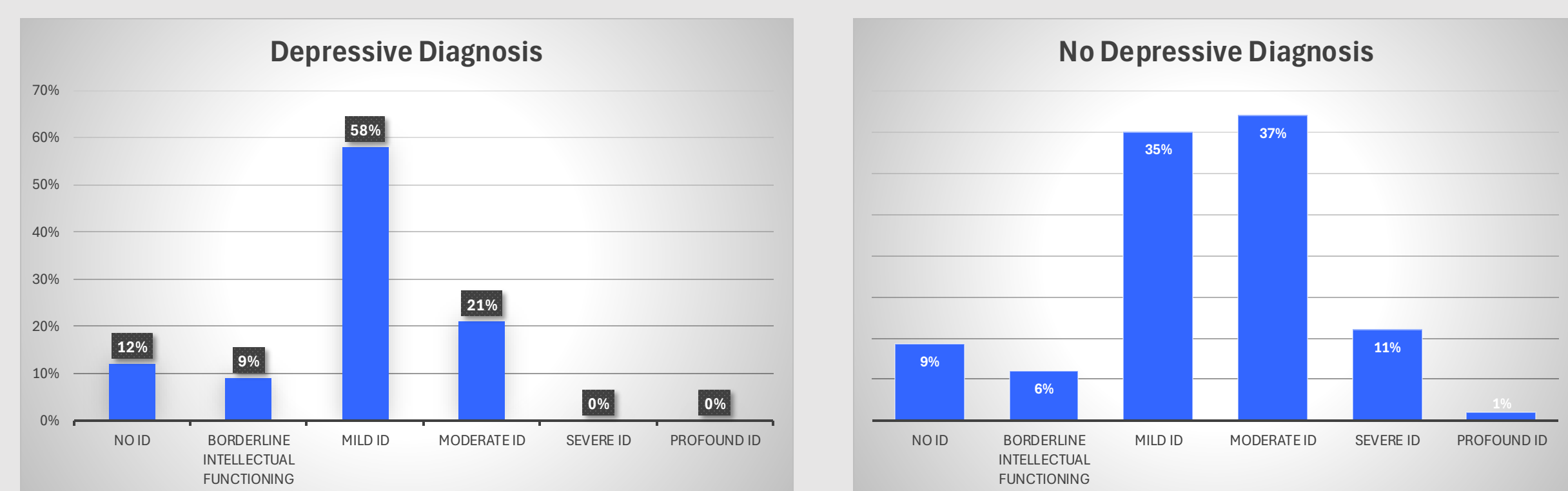
After synthesizing the data, 27% of enrolled START participants had a depressive diagnosis in SIRS with 73% having no depressive disorder. There were 45 female participants and 85 male participants ranging from 9 years old to 61 years old. Among those in the group with a depressive diagnosis, 70% had one or more medical diagnoses associated with pain. The other 30% had no medical diagnosis in SIRS. True to discovery while reading literature on this topic, the majority of people with a depressive disorder had a mild ID, borderline intellectual functioning, or no ID (the individuals with borderline or no ID are on the autism spectrum). The remaining people diagnosed with a depressive disorder (21%) were in the moderate ID category with severe/profound ID showing 0%. In those showing no depressive disorder diagnosis, it was equal with 50% of those with mild ID, borderline intellectual functioning, and no ID with the other 50% falling under the moderate/severe/profound level of ID.

DEPRESSIVE DISORDER DIAGNOSIS / NO DEPRESSIVE DISORDER DIAGNOSIS pie charts
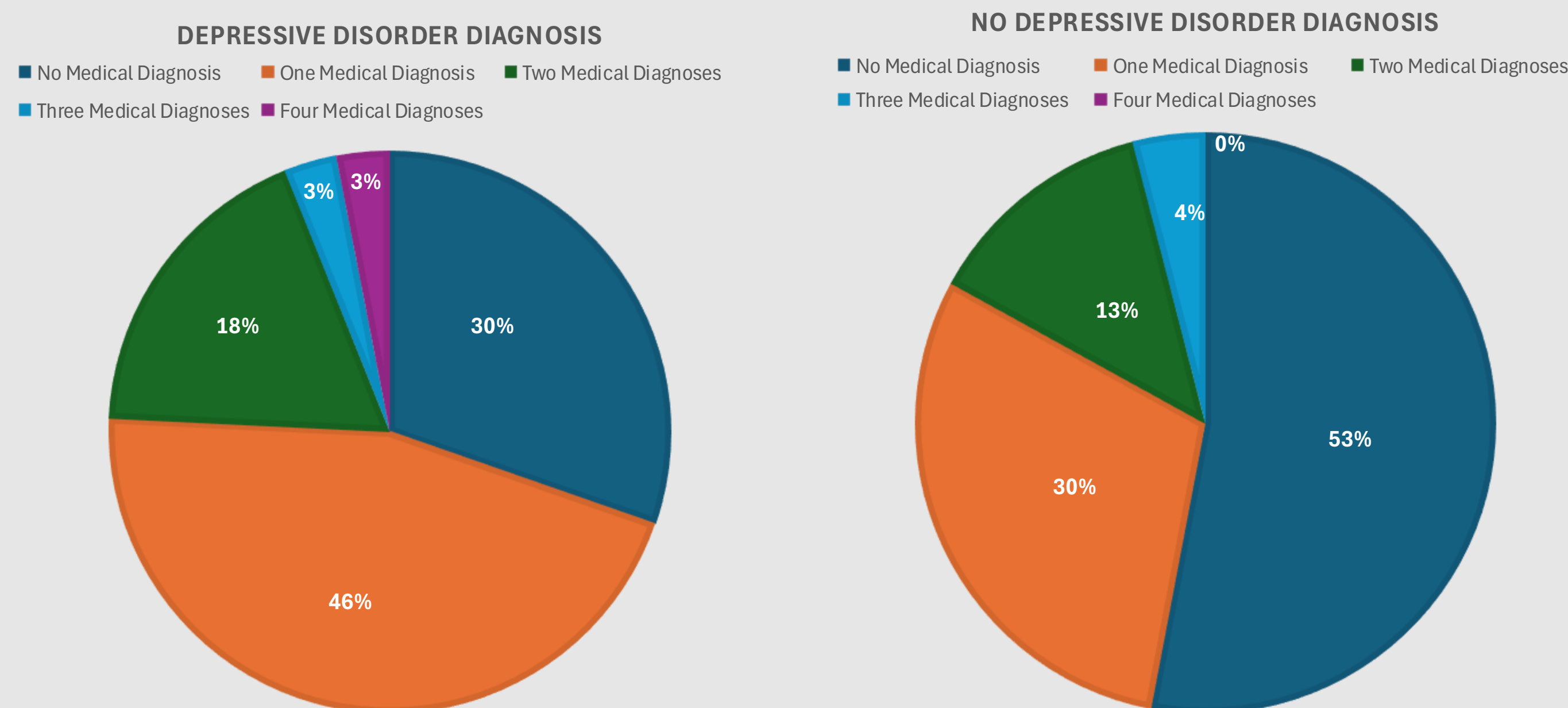
The findings related to the number of medical conditions for those who had a depressive disorder diagnosis in the pie chart above are clearly noted. 46% carry one medical diagnosis that would cause pain and could be associated with the reason for the depressive diagnosis. 18% of this group carry two diagnoses that may cause pain, and 3% have three and four medical diagnoses that are known to cause pain. The other 30% who have no medical diagnosis, but have a depressive diagnosis, are also diagnosed with a trauma and other stressor related disorder, which explains the depressive disorder given.

The findings related to the number of medical conditions for those who did not have a depressive disorder in the pie chart above are clearly noted. 53% carry no medical diagnoses considered to be pain related. 30% had one medical diagnosis that would cause pain and warrant considering a depressive disorder diagnosis. 13% of the participants in this study carry two medical diagnoses that could cause significant pain and distress. 4% carry three pain inducing medical conditions. None of the participants in this category had four or more medical conditions associated with pain.

(Right column)

From among the sample group that did have a depressive disorder (coded in shades of blue), the number of people with depression and at least one co-occurring medical diagnosis causing pain was more than twice the number of those with no comorbid medical conditions. In contrast, the sample of people without a depressive disorder (coded in green) was far larger and the number of people at greater risk of depression (with an ID and one or more medical conditions causing pain) outnumbered the entire group diagnosed with a depressive disorder. 38% of the sample did not have a medical condition or a depressive disorder and was, therefore, at lower risk for depression. Only one individual with Moderate ID in our sample was diagnosed with a depressive disorder without a comorbid medical diagnosis. All 9 remaining people diagnosed with a depressive disorder in the absence of a medical diagnosis had an IQ in the Mild ID range or higher.

All Participants Across All Intellectual Disability Levels

Discussion

In this sample of people supported by NC START West, medical complexities are common, and depressive disorders are not diagnosed as often as one would expect. Based on the literature, a contributing factor may be due to the difficulty that this population has verbally expressing internal experiences like sadness or hopelessness as well as other symptoms often associated with pain and a depressive disorder. Without this information, clinicians feel they do not have the information needed to make a depression diagnosis, and there is a misinterpretation of symptoms. Often, people with ID gain diagnoses that just look at external symptomology, assuming symptoms such as irritability and aggression indicate psychosis because the source is unknown, and diagnostic overshadowing occurs. For example, when pain is not addressed, a person's depression can worsen, and more externalizing behavioral challenges can occur.

In Chapter 12 of *The Diagnostic Manual-Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID 2)*, the authors (Charlot et al, 2016) note when taking depression into consideration for someone who is diagnosed with ID, people with ID are more likely to have a depressive disorder than someone who does not have an ID diagnosis. As previously noted, the challenges in diagnosing depression with the ID population include overreliance of caregiver report due to communication challenges. This situation effects accuracy in analyzing critical factors related to diagnosing depression such as pain level and other medical symptoms, potential medication side effects, and mood patterns, as well as a general misunderstanding of the function of observable challenging behaviors. For example, a person with mild ID is more able to share their feelings of hopelessness and despair and are more likely to gain a diagnosis of depression than a person with moderate ID.

Providing psychoeducation to caregivers about the relationship of depression for people diagnosed with ID and the contributing factors such as potential medication side effects and the prevalence of pain for someone who has musculoskeletal disorders, gastrointestinal disorders, cerebral palsy, dental problems, and endocrine/metabolic conditions, is essential in addressing misdiagnosis. With education comes greater ability to recognize and support someone who is experiencing depression because of symptoms they may be experiencing and cannot express. Identifying the imbalance of depressive disorder diagnosed in the ID population, bearing in mind that multiple medical conditions that could be co-occurring are known to present symptoms, such as pain and mood lability, is a complex issue. Therefore, initial exploration of possible physical discomfort is warranted when addressing a person's behavioral presentation. The START Information Reporting System compiles the data elements to continue this discussion and support people in gaining the adequate mental health care to treat what may be a depressive disorder that has previously been missed.