NCI DATA BRIEF

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What does NCI tell us about adults with intellectual and developmental disabilities who are taking prescribed medications for anxiety, behavior challenges, mood disorders or psychotic disorders?

The first effective antipsychotic medications to treat mental illness were introduced in the early 1950s and many new drugs to treat conditions such as anxiety, OCD, depression, bi-polar disorder, etc have been developed since then. Due to the effectiveness of such medications in reducing challenging behavior, the same medications were often prescribed for people with intellectual and developmental disabilities to treat various mental health diagnoses and, in too many cases, to simply control challenging behavior. As the serious side effects (e.g. Tardive Dyskinesia) of these medications became apparent, stronger regulation and even litigation focused on the overuse of these drugs. Though medications have certainly improved the quality of life for many, there continue to be concerns that people with ID/DD are more vulnerable than the general population to being over medicated and subject to de facto chemical restraint. Due process and informed consent procedures may be lacking and medications may be substituted for active habilitation and used for control.

The National Core Indicators (NCI) project provides important information on the experiences of people with ID/DD with the service delivery system. This Data Brief is a snapshot of the use of medications in public ID/DD systems and the relationship of such use to health and wellness.

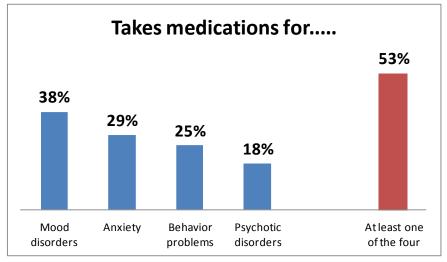
SAMPLE

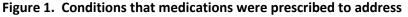
The information in this Data Brief is drawn from the 2010-2011 National Core Indicators (NCI) Adult Consumer Survey of 8,796 adults from 15 states¹. The Background section of the Survey includes four items that reflect whether the person is taking medications specifically to address three mental health conditions: 1) mood disorders, 2) anxiety, 3) psychotic disorders, or 4) behavior challenges. The analyses exclude 406 people for whom there were insufficient data to determine whether a person was taking at least one medication for any of these conditions. The final data set includes 8,390 people.

¹ The 2010-2011 NCI Adult Consumer Survey Report included: Alabama, Arkansas, Florida, Georgia, Illinois, Kentucky, Louisiana, Maine, Missouri, North Carolina, New Hampshire, New York, Ohio, Oklahoma, and Pennsylvania.

MEDICATIONS FOR MOOD, ANXIETY, PSYCHOSIS, AND BEHAVIOR CHALLENGES

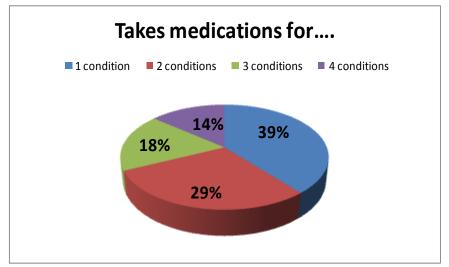
Fifty three percent of people in the data set (4,441 individuals) were taking medication to address at least one of the three mental health conditions or behavior challenges. Most common was medication to treat a mood disorder; 38% of the sample was taking medication for a mood disorder. Next most common was medication for anxiety (29%), followed by medication for behavior problems (25%). Least common was medication for psychotic disorders - 18% of the sample was prescribed medications for treatment of a psychotic disorder. This information is presented in Figure 1 below.





Of those taking medications for at least one of the above purposes and for whom data were available on all four items (N=3,977), 39% were taking medications for only one, 29% for two, 18% for three and 14% were taking medications for all four reasons (Figure 2).

Figure 2. Number of conditions medications were prescribed to address



DIAGNOSES / ASSESSED NEED FOR SUPPORT

The Background Section of the Adult Consumer Survey also collects information on whether a person has been determined to need support to manage self-injurious, disruptive or destructive behavior, as well as whether a person has a psychiatric or mental illness diagnosis. Thus it is possible to compare medication use with assessed need for behavior support and psychiatric diagnoses.

Forty nine percent (49%) of people who were determined to need some amount of support for one of the three types of behavior were taking medications to address challenging behavior. Eight percent (8%) of those whose evaluations showed no need for behavioral supports were taking prescribed medications for challenging behavior (Table 1). Amongst people taking medications for behavior challenges, 18% were determined to not need behavioral supports.

Table 1. Need for behavior supports and medications to address behavior challenges

	Did not take medications for behavior problems	Took medications for behavior problems	Total
Support not needed for behavior problems	92%	8%	100%
Support needed for behavior problems	51%	49%	100%

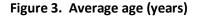
Eighty-eight percent (88%) of people with a psychiatric diagnosis were taking medications for mood, anxiety, or psychotic disorders. However, thirty percent (30%) of people without such diagnoses were also taking medications for at least one of these conditions (Table 2). Amongst people taking medications for mood, anxiety or psychotic disorders, 41% did not have a psychiatric diagnosis.

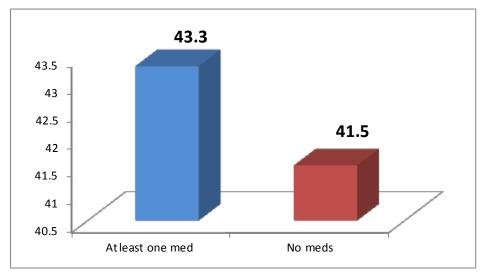
	Did not take medications for mood, anxiety or psychotic disorders	Took medications for mood, anxiety or psychotic disorders	Total
No mental illness/ psychiatric diagnosis	70%	30%	100%
Mental illness/ psychiatric diagnosis	12%	88%	100%

DEMOGRAPHIC PROFILE

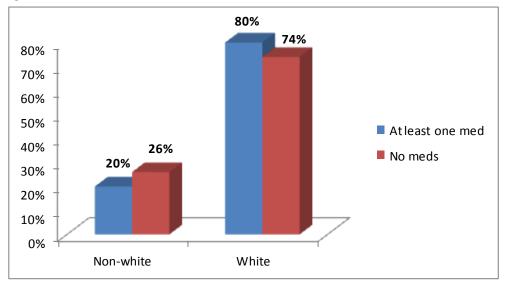
Adults with intellectual and developmental disabilities who were taking medications for one of the three mental health conditions or behavior differed from those who did not take any medications in several ways.

As shown in Figure 3, those taking medications had a mean age of 43.3 years and were on average almost two years older than those not prescribed medications (mean age = 41.5 years).





Those who took medications were slightly less racially diverse; 80% were white compared to 74% of those not taking medication identified as white (Figure 4).





There were significant differences in living arrangements between those taking medications and those who were not (see Figure 5). Those who were taking medications were significantly more likely to be living in a group home (35% vs. 19%), and much less likely to be living with parents or relatives (22% vs. 47%).

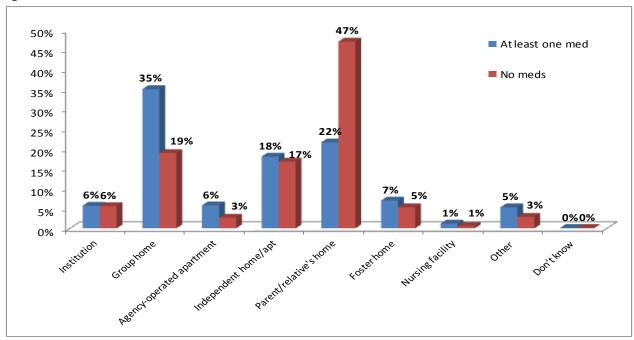


Figure 5. Residence

Individuals taking medications also had a different profile with respect to their level of intellectual disability (ID) than did individuals who were not. Those taking medications were slightly less likely to have the label of profound intellectual disability and more likely to have the label of mild ID (Figure 6).

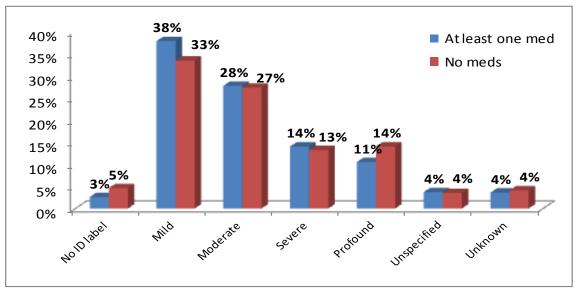


Figure 6. Level of ID

People taking medication were slightly less likely to have a diagnosis of cerebral palsy (10 % vs. 20% of those not taking medications), a physical disability (8% vs. 12%), or Down syndrome (5% vs. 13%) (Figure 7). On the other hand, they were significantly more likely to be diagnosed with an autism spectrum disorder (13% vs. 7%).

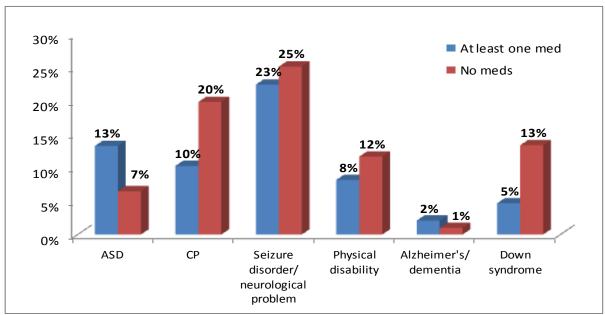


Figure 7. Other diagnoses

MEDICATIONS AND HEALTH

Individuals taking medications for mood, anxiety, psychosis or behavior were less likely to be in very good or excellent health (38%, compared to 43% of those not taking medications). Those taking medications were more likely to be in fairly good (56% vs. 52%) or poor health (6% vs. 4%) (Figure 8).

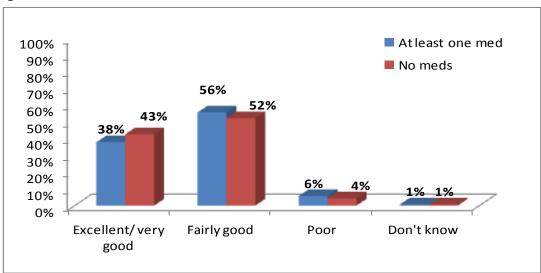
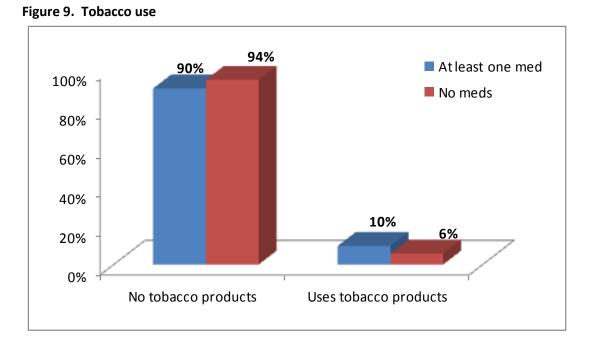


Figure 8. Health

Those taking medications were slightly more likely to smoke or use tobacco products (10% of them did, as compared to 6% of people not taking medications) (Figure 9).



Adults taking medications were more likely to be obese or overweight than adults not taking medications (see Figure 10). The difference is especially pronounced in the percentage of people who are obese – 29% of people not taking medications had a Body Mass Index (BMI) that fell in the obese range, compared to 37% of people using medications.

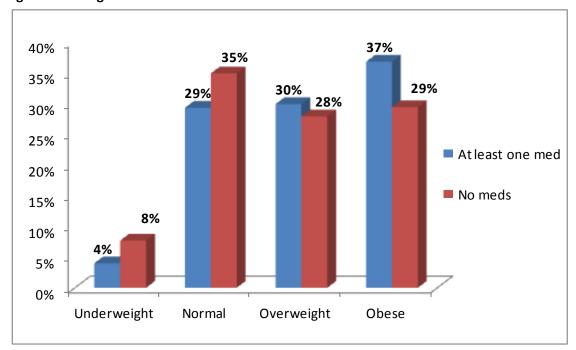


Figure 10. Weight

SUMMARY OF FINDINGS

Data collected in 2010-11 by the National Core Indicators Adult Consumer Survey revealed significant findings about medication prescription for mood disorders, anxiety, behavior challenges and psychotic disorders.

- 53% of the sample was taking medications for at least one of three mental health conditions or challenging behavior. Most commonly, medication was prescribed to treat mood disorders (38% %).
- ✤ 14% of the sample was taking medications for all four reasons.
- 88% of people with a psychiatric diagnosis were taking medications for at least one of the following: mood, anxiety or psychotic disorders.
- However, 30% of people without a psychiatric diagnosis were also taking medications for mood, anxiety or psychotic disorders.
- Amongst people taking medications for mood, anxiety or psychotic disorders, 41% did not have a psychiatric diagnosis.
- 49% of people who were determined to need some amount of support for one of the three types of behavior were taking medications to address challenging behavior.
- Eight percent (8%) of those whose evaluations showed no need for behavioral supports were taking prescribed medications for challenging behavior.
- Amongst people taking medications for behavior challenges, 18% were determined to not need behavioral supports.

Demographically, compared with individuals who were not taking any of these medications, people using medication for at least one of the four conditions were:

- Slightly older.
- Slightly less racially diverse (more likely to be white).
- More likely to live in group homes and less likely to live with parents or relatives.
- More likely to have the label of mild intellectual disability than moderate, severe or profound.
- More likely to be diagnosed with autism spectrum disorder and less likely to have cerebral palsy and Down syndrome.

The data also showed that people taking medications were:

- Less likely to be in very good or excellent health.
- More likely to use tobacco products.
- More likely to be obese and less likely to be of normal weight.

The data illustrate the extent of medication usage among adults with ID/DD for mental health conditions and behavioral challenges. There are clear differences between those taking medications and those not. There are demographic differences as well as differences in outcomes such as health. Further analyses

are needed to determine the impact of taking medications on other outcomes, while controlling for pertinent factors that may affect those outcomes.

LIMITATIONS AND ADDITIONAL ANALYSES

The analyses presented above are descriptive in nature. It is possible that some of the differences between those taking medications and those not that were found here are due at least in part to other factors besides medication usage. Further analyses to control for factors other than medications will be performed; results will in a peer-reviewed journal.



National Association of State Directors of Developmental Disabilities Services