

**TITLE: *MEDICATION SIDE-EFFECTS AND MEDICAL PROBLEMS OF INDIVIDUALS WITH IDD AND BEHAVIORAL HEALTH CHALLENGES ADMITTED FOR EMERGENCY RESPITE CARE.***

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**OVERVIEW/ABSTRACT:** People with IDD are increasingly exposed to numbers of psychoactive medications. While there does not appear to be a strong evidence base for reported practices, these individuals may not be reliable at reporting side effects. There is risk that irritability related to adverse drug events (ADEs) could prompt increased use of potentially offending agents. To seek a greater understanding of what are the side effects experienced by people with IDD treated with psychoactive medications, we reviewed the results of our RN's administration of the Matson Evaluation of Drug Side Effects (MEDS) for 43 individuals' crisis admissions to 2 of our Centers (The NC START East and West). We explored the type and frequency of psychoactive medication side effects identified by the screen, and looked for any possible relationship to the type and number of psychoactive medications reported for the group. We identified symptoms that may have acted as one of multiple influences on individuals' distress prompting the admission. A detailed case example is provided highlighting the deleterious effects of drug side effects on mental status, mood and behavior on ways that may mimic an acute mental illness episode.

**SPECIFIC AIMS:**

- (1) Review findings from administration of a validated side effects screening tool developed for people with IDD in a small group of individuals admitted for crisis stays to our respite centers, and describe types and rates of problems.
- (2) Explore possible relationships between side effects identified by the screen, and the medications these individuals were prescribed at the time, age group, gender and presence of an ASD.

**BACKGROUND**

Recent reports suggest that people with ID may increasingly receive treatment with multi-drug regimens (Esbensen, Greenberg, Seltzer & Aman, 2009, M.G Häßler, Thome, & Reis, 2015, Lott et al., 2004). Most people with ID are referred for acute mental health care when they display aggressive behaviors, and their pharmacotherapy is often aimed at its reduction (Matson & Neal, 2009, Tsakanikos et al., 2006). This is unlike most psychiatrically treated individuals for whom pharmacotherapy is overwhelmingly aimed at the amelioration of symptoms of Axis I psychiatric syndromes (Sheehan, Hassiotis, Walters, Osborn, Strydom, & Horsfall, 2015). Despite expert consensus that all efforts should first be made to identify any acute psychiatric conditions, and that treatment using various modalities in combination is preferred, more and more individuals with ID may be getting medication as the primary approach to their problem behaviors (Kroese, Dewhurst, & Holmes, 2001). Of special concern is the limited investigation of side effects and adverse drug events (ADEs) experienced by people with ID (Valdovinos et al., 2005). This is especially worrisome because people with ID may not accurately complain, or may not complain at all, when suffering from distressing or even dangerous side effects. Individuals with ID rarely control their own pharmacotherapy (Kroese, Dewhurst, & Holmes, 2001). Most often, decisions are made by others to continue medications or add medications, and whether any apparent side effects are "well tolerated." Few studies discuss rates or risk factors for ADEs. Valdovinos and colleagues (2005) found that the frequency of medication changes correlated with number of possible side effects. They speculated that having frequent medication adjustments might provoke more ADEs. High rates of ADEs have been found in the few studies of antipsychotic drug use including subjects with ID or ASD, including weight gain, sedation, withdrawal dyskinesias, other Parkinsonian symptoms and constipation.

In general, individuals with ID treated with psychoactive medications may experience uncomfortable or distressing side effects, but their altered mood and behavior may be viewed as representing a worsening

of their mental health problem, sometimes prompting the addition of yet more medications. Increased detection of side effects that cause discomfort and distress could potentially improve *behavioral* outcomes for patients with ID treated with psychoactive medications.

Studying the nature of side effects identified among people with an IDD who are treated with psychoactive medications may help to inform strategies to raise awareness of them among caregivers and prescribers. An additional goal would be to prevent additions of psychoactive medications to treat altered mood and behavior resulting from a missed medication side effect. The START program offers a unique opportunity where the services and model already includes key consultation and education components that might provide systems of care with alternatives to over reliance on psychoactive medications, especially when there is a lack of a multi-modality approach to the individual's care.

## **METHODS**

START clients are sometimes admitted for a crisis stay at a START Resource Center. These are 4 bed centers where adults aged 18 and up enrolled in START services, are provided with assessment and care while coordinators work with the community system to facilitate a clinically informed return to their community. During these stays, one component of assessment is the administration by Center nurses of The Matson Evaluation of Drug Side Effects (MEDS) is a 93-item scale designed to assess side effects common to psychotropic medication use with a psychometrically established checklist. Parents/caretakers familiar with the individual rates each item. The MEDS has been carefully reviewed in samples of people with IDD and found to have excellent consistency across raters and good internal consistency. Items are rated for both severity and duration (see additional hand-outs).

There are 9 areas or domains covered including:

- 1) Cardiovascular/Hematologic
- 2) Gastrointestinal
- 3) Endocrine/Genitourinary
- 4) Eye/Ear/Nose/Throat
- 5) Skin/Allergies/Temperature
- 6) CNS-General
- 7) CNS-Dystonia
- 8) CNS-Parkinsonism/Dyskinesia
- 9) CNS-Akathasia.

Results of the MEDS are shared with community teams, and prescribers to raise awareness while there is ongoing education in the community systems of care to increase capacity for identification of medical problems and medication side effects that may be mistaken for an acute exacerbation of an existing mental health condition.

In the present review, the results of the MEDS from 42 unduplicated crises stays at two different START Resource Centers were examined retrospectively to identify initial patterns that might inform a later more systematic study. These adults (aged 18 and up), like all START enrollees, have an IDD diagnosis and co-occurring significant mental health or behavioral challenges. The length of stay is variable, but a goal is to have initial crisis stays of about 30 days to allow for assessment and development of treatment recommendation including specific strategies to inform improved mental status and a successful return to community/home. In this endeavor, START employs multidisciplinary and multi-modality techniques and includes a focus on positive and strength based strategies while actively engaging the system of care.

**SIRS database**

START employs a custom online database, the START Information Reporting System (SIRS). This data entry platform is accessed through an internet browser and captures many variables including the MEDS results. All information entered and extracted from SIRS is fully de-identified. Monthly, quarterly and annual data reports aid the START teams in monitoring progress and inform adjustments to practice to improve outcomes. The present review of data is preliminary and descriptive.

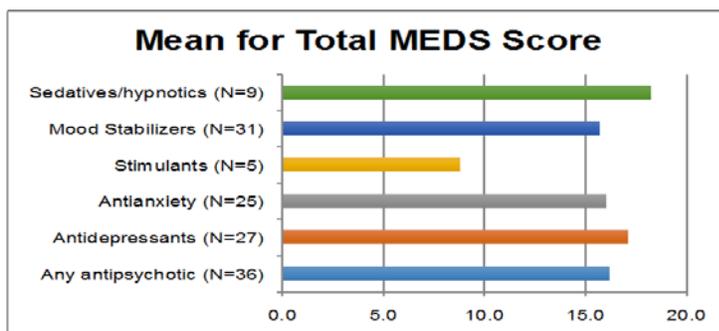
**RESULTS for the Present Review**

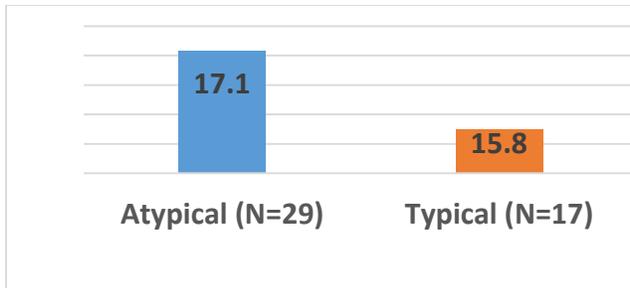
In this preliminary look at the nature of possible medication side effects reported by our respite center RN based on administration of the MEDS, we found some potential patterns that may be further studied in future more systematic and prospective investigations.

We examined whether there was an association between age group and having more side effects. Though the mean severity rating was higher for those 26 to 45 years of age, the rating for the small older age group (n only 3) was not higher still, as expected.

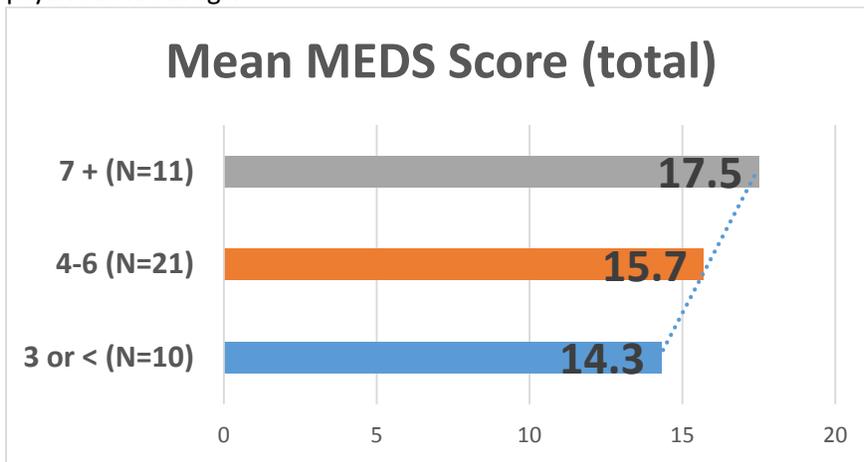
MEDS Category	18-25 (N=21)	26-45 (N=18)	46+ (N=3)
Cardio	0.7	1.6	0.0
CNS-beh. Akathisia	4.7	4.4	3.5
CNS-Dystonia	0.1	0.3	0.0
CNS-General	3.8	4.7	2.7
CNS-Parkinsonian	0.8	2.2	1.7
Ear Nose Throat	1.3	1.6	2.3
Endocrine	0.9	1.1	0.7
Gastro	1.4	2.4	2.0
Skin	0.4	1.7	0.0
<b>TOTAL</b>	<b>13.8</b>	<b>18.6</b>	<b>11</b>

Individuals receiving a variety of medication sub types had mean severity ratings that were uniformly high except for those reported for stimulants.

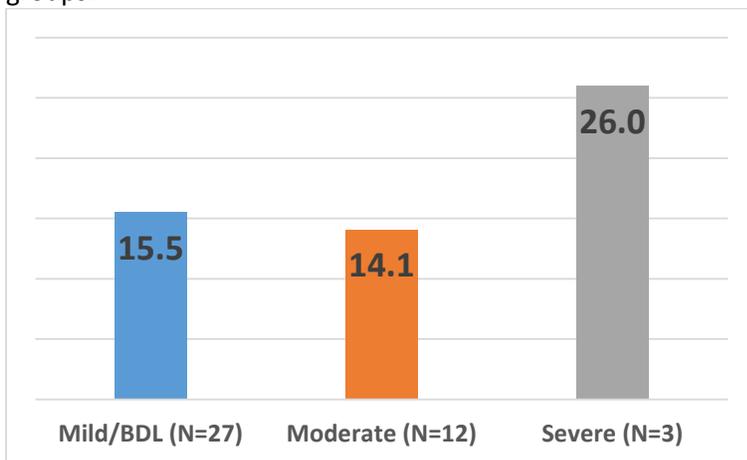




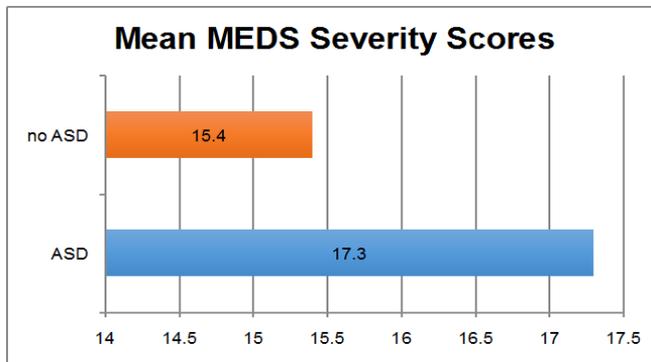
As expected, it appeared that there may be greater risk for side effects with increasing numbers of psychoactive drugs.



We also looked at the trends in side effects severity scores as these might be associated with level of IDD. Mean severity scores for individuals with severe IDD diagnoses was much higher than for the other groups.



Individuals carrying a diagnosis of ASD also had higher mean severity of side effects scores.



### LIMITATIONS

The present examination of possible medication side effects involves a small sample, so that stratification into sub groups to examine correlates suffered from a lack of cell sizes adequate to prevent skewing of data from any outliers. The review was also retrospective in nature. However, this very preliminary look at the very concerning problem of medication side effects can help in planning future larger prospective reviews.

### DISCUSSION:

We reported on an initial examination of the possible medication side effects of a series of 42 adults with IDD admitted for a crisis stay at our Resource Centers, based on administration of a psychometrically established screening tool, the MEDS. Remarkably, these individuals were treated with very large numbers of psychoactive medications with 26% prescribed 7 or more at the same time. Some possible patterns emerged including greater risk for side effects in association with level of IDD. This was the most striking finding. It may be that having more brain impairment confers greater risk of side effects from medication that impact neurotransmitter and neurological functioning. For example, Caroff and colleagues (2011) noted that cognitive impairment and other baseline brain impairments are associated with elevated risk for movements disorders in patients treated with antipsychotic drugs. However, an additional possibility is that people with more severe cognitive impairments also have more functional communication challenges, and are less likely to report discomfort from a medication side effect. Caution may need be even greater when prescribing psychoactive medications for this highly vulnerable group of people with IDD.

As people age, they may experience more adverse effects of multidrug regimens. However, we had so few people in the older age group, this was not found in the present review. We did see the middle age group (age 26-45 years) had a higher mean rating for severity of side effects than did the younger age group, but also greater than the older age group.

We also found a trend suggesting possible elevated risk associated with a diagnosis of ASD. This may also be a group that has a lot of challenges to functional communication, and may be poor at reporting side effects.

In general, our report highlights a concern very complicated and potentially high risk multi-drug treatments may be common among individuals with IDD experiencing a behavioral health crisis. In at least some cases, psychoactive medications appeared to be prescribed to treat the mental status, mood and behavior changes that were caused by missed drug side effect. This occurs in the context of research and experts reporting that "More evidence is needed of the efficacy and safety of psychotropic drugs in this group, particularly when they are used for challenging behavior," (Tyrer et. al, 2014). The

need for increasing the awareness and education regarding alternatives to what appears to be non-evidence based reliance on use of multiple psychoactive drugs in the population seems much needed.

### **NEXT STEPS**

A more in depth review of MEDS findings across the entire START network is in planning stages. Locally (NC START East), we are currently working on additional plans to provide a series of trainings that specifically address recognition of drug side effects in people with IDD to our community partners. In a subsample of individuals served by our teams, we hope to pilot a new one page communication tool to be presented to prescribers at outpatient mental health appointments summarizing possible medication side effects observed by caregivers or identified during Center stays, and then to follow up with prescribers to determine if this changed prescribing practice over time.

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