

Disclosure Statement: The authors testify that they have no relevant relationships to disclose, including no industry affiliation, and no conflicts of interest, financial or otherwise.

1 INTRODUCTION

Patients with intellectual disability (ID) are at a particular disadvantage in adulthood. They frequently become lost to care when they transition out of the pediatric system. Their predominant behavioral problems can lead to missed diagnoses, multiple psychiatric diagnoses, polypharmacy and even legal involvement. They frequently face housing challenges and a downward social trajectory. Policies for integrated care to address this treatment gap are much needed.

2 METHODS

This is a retrospective case series of 34 patients referred to neuropsychiatry for behavior management. The neuropsychiatry service was an outreach component of an integrated care approach in a suburban area. The model of care is depicted in **Figure 1**. Outcome measures were changes in diagnostic complexity and in frequency of disruptive behaviors after assessment within the care model.

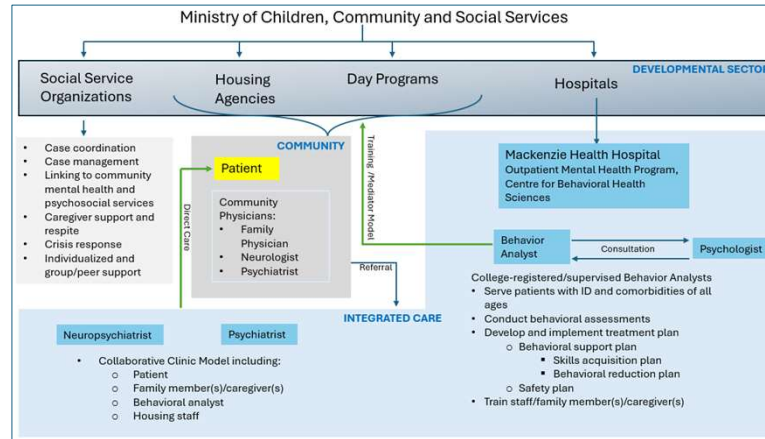


Figure 1 - Patient-Centered Integrated Care Model

3 RESULTS

Table 1 shows the baseline characteristics of the cohort, most with severe ID and predominantly middle-aged males with Autism Spectrum Disorder.

Figure 2 shows the change in psychiatric diagnoses before and after neuropsychiatric assessment within the integrated care model.

Before assessment, 19/34 patients carried multiple psychiatric comorbidities, most commonly schizophrenia spectrum disorders, to explain aberrant behavior. 17/34 were on antipsychotics (APs).

After assessment, 16/34 had psychiatric comorbidities, most commonly depression. Only 8/34 were on APs.

Patients whose psychotic symptoms were confirmed on clinical assessment were determined to have a secondary psychosis, e.g. due to epilepsy, deep brain stimulation and mega cisterna magna. In the remainder, quite a few cases showed a manifold semiology to the behavioral disturbance. These were counted towards a diagnosis of bipolar disorder in Figure 2.

Biological Sex	Males:	58.8%
	Females:	41.2%
Age	Range:	18-64 yrs
	Mean:	33 yrs
	Males:	35 yrs
	Females:	31 yrs
Severity of ID	Severe, non-testable:	79.4%
	Mild, FSIQ 66-69:	20.6%
Cause of ID	Autism Spectrum Disorder:	41.2%
	Other:	20.6%
	Aicardi Syndrome	
	Dravet Syndrome	
	Cardiofaciocutaneous Syndrome	
	Fetal Alcohol Syndrome	
	Leukemia-meningitis-hydrocephalus	
	Birth hypoxia	
	Multiple brain cavernomata	
	No known cause:	20.6%
	Cerebral Palsy:	6%
	Dandy-Walker Variant:	6%
	Cerebral dysgeneses:	6%
Medical Comorbidities	Epilepsy:	64.7%
	Metabolic syndrome (obesity, hypertension, dyslipidemia and obstructive sleep apnea):	23.5%
	Other neurological disorders (stroke, movement disorders):	14.7%
Reasons for Referral	Pharmacotherapy for aggression:	100%
	Diagnostic clarification:	100%
	Polypharmacy:	100%
	Seizure control:	17.6%

Table 1 - Baseline Characteristics of the Cohort, N=34

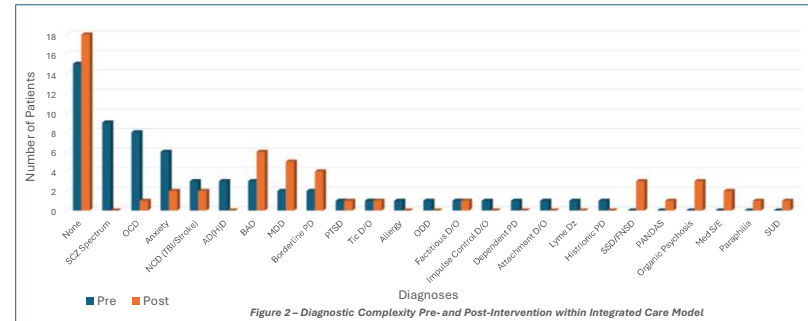


Figure 2 - Diagnostic Complexity Pre-and Post-Intervention within Integrated Care Model

Streamlining of diagnoses allowed for more targeted treatment, rather than reflexive use of antipsychotics for behavior management. Treatment outcome is shown in **Figure 3**.

Figure 4 shows the improvement in behavior within the categories shown, based on data collected by residential staff. Also, qualitative feedback from caregivers indicated that this translated to increased engagement in daytime activity and increased successful home visits.

Of the 17 patients previously treated with APs, 11 responded to antiepileptic drugs (AEDs) instead. This trend towards discontinuation of APs and more successful use of AEDs was favorable, as the two most common medical comorbidities were epilepsy and metabolic syndrome. Even in 2 patients without diagnoses of epilepsy or bipolar disorder, AEDs were successful at managing behavior where APs were not.

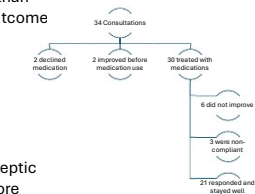


Figure 3 - Treatment Outcome (N=34)

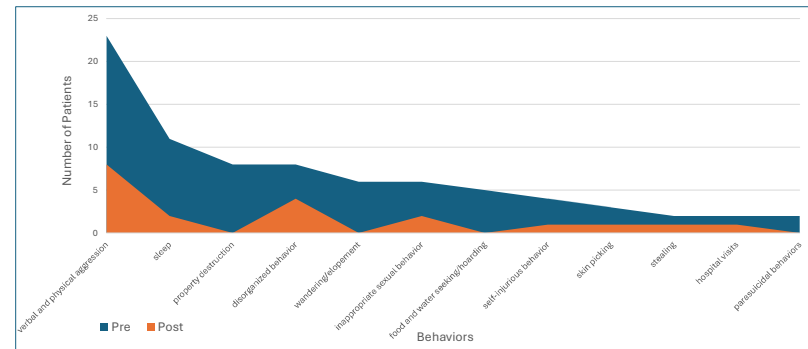


Figure 4 - Frequency of Behavior Disturbance Pre- and Post-Intervention within Integrated Care Model

4 DISCUSSION

With a predominantly behavioral phenotype in patients with ID, psychiatric diagnosis is challenging, with risk of both 'polydiagnosis' and its converse, 'diagnostic overshadowing.' Demonstrably, in our case series several patients were referred with multiple diagnoses and polypharmacy. At the same time, there were missed diagnoses of depression, bipolar disorder, medication side effect and somatic symptom disorder, with frequent diagnoses of psychosis instead. Our comorbidity rate, with depression as the most common comorbidity, is consistent with the more rigorous, though limited, data in this population. The frequency of bipolar semiology of behavioral disturbances was surprising. The preferential response of behavioral disturbances to AEDs versus APs, even in patients without epilepsy or bipolar disorder, deserves further investigation. Challenges included refusal of care, compliance issues in mild ID with maintained decision-making capacity, and lack of response to treatment, which altogether occurred in 11/34 cases. Nevertheless, this approach may offer a potential for improved health outcomes, over the default model of isolated care.

5 CONCLUSIONS

An integrated and collaborative care approach may help to address the treatment gap in adult patients with ID and neuropsychiatric comorbidities. Additionally, given the limited data in this population, standardized, comprehensive assessments and formulation of treatment plans within such a model may create better opportunities for more rigorous research. Altogether, this offers a potential for improved evidence-based clinical practice, health and behavioral outcomes, and overall quality of life in this patient population.