

New Frontier: The First Year of an Adult Neurodevelopmental Disabilities Clinic

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Abstract:

BACKGROUND AND OBJECTIVES: As patients with Neurodevelopmental Disorders (NDD) transition from pediatric to adult healthcare systems, they often have difficulty finding providers who address their NDD-related needs. In response to this care gap, a new consultation clinic was established in an Adult Neurology Department within a Behavioral Neurology Clinic to address neurodevelopmental concerns of these adult patients. In this study, we aim to characterize the population of adult patients with NDD seen in the Adult NDD Clinic in its first year.

METHODS: Data were obtained by a retrospective chart review of all patients with neurodevelopmental disorders seen in the Adult NDD clinic from September 2020 through December 2021.

RESULTS: Of the 86 patients seen in the adult NDD clinic, the average age was 34 years (standard deviation = 15), ranging from 18 years to 74 years. Developmental diagnoses included intellectual disability (63%), Autism Spectrum Disorder (47% of patients), Down syndrome (15%), cerebral palsy (9%), and other genetic disorders (26%). Comorbidities addressed included behavioral concerns (34%), anxiety (29%), seizures (22%), and depression (15%). Behavioral and/or mental health concerns initiated 65% of patient visits. Other common concerns included those relating to developmental challenges or progress, Autism Spectrum Disorder, movement difficulty, and cognitive decline. The most common recommendation made was to begin or increase exercise (59%), followed by facilitating connection to community, social, and employment resources.

DISCUSSION: This paper describes adult patients with NDD seen in a new outpatient specialty Neurology clinic with comorbidities, diagnoses, concerns, and recommendations that are similar to, but also distinct from those addressed in other adult Neurology clinics. This study addresses the need and feasibility of tailoring care for the diverse population of patients with NDD in an adult Neurology setting.