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## Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction

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### ABSTRACT

**Background:** Adults with Autism Spectrum Disorder (ASD) encounter many difficulties finding and accessing health care services. Despite this, few studies have considered the health service use patterns of adults with ASD without intellectual disability (ID).

**Objectives:** The current study examines a diverse range of medical and mental health services and supports, as well as adults' personal experiences accessing and using these services, barriers to service use, and reported unmet service needs.

**Methods:** Forty adults (ages 18–61 years) with ASD without ID completed surveys every two months about their health service use for a total of 12–18 months. Bivariate analyses were conducted to understand the individual demographic and clinical factors associated with rate of service use, satisfaction with services, and barriers to health care.

**Results:** Results indicated that, beyond a family doctor, the most commonly used services were dentistry, individual counseling, and psychiatry. Individuals who had medical problems experienced significantly more barriers to service use than those who did not, and those who had medical and mental health problems were less satisfied with services.

**Conclusions:** Findings highlight the challenges adults with ASD without ID face accessing appropriate, quality services to meet their needs, particularly those with complex medical and mental health issues. Service providers must strive to provide adequate health care to this population who may become distressed if their needs are left unmet.

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### 1. Introduction

Individuals with Autism Spectrum Disorder (ASD) experience challenges with social communication and restrictive patterns of behaviour and interests<sup>1</sup> well into adulthood. Individuals with ASD present with a wide range of abilities; however, a large proportion of affected individuals do not show a clinically significant delay in cognitive and language development<sup>2</sup> and are often referred to as high functioning, herein referred to as ASD without intellectual

disability (ID). Despite their “high functioning” label, adults with ASD without ID often struggle to find employment, maintain social relationships and live independently.<sup>3–5</sup> Moreover, individuals with ASD without ID may experience higher rates of mental health concerns, such as depression and anxiety, compared to those with ASD and lower IQs.<sup>6,7</sup> Regardless of these complex needs, limited access to supports and services has left many adults with ASD without ID understudied within the health services literature and underserved within their communities. The present study seeks to better understand the service needs of this vulnerable population by analyzing the self-reported health service utilization patterns of adults with ASD without ID tracked over 12–18 months.

Substantial research suggests families of children with ASD report higher overall health service use, greater accessibility

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barriers and lower satisfaction with services when compared to typically developing peers.<sup>8–12</sup> Compared to the literature on children, fewer studies have been conducted on health service use, barriers, and satisfaction with health services among adults with ASD overall, and even less is known about adults with ASD without ID. In a recent<sup>13</sup> caregiver report survey of individuals with ASD of mixed functioning levels (i.e. with and without ID), adults with ASD were reported to have higher unmet service needs as compared to youth in middle or high school with respect to speech therapy, social skills training, occupational therapy, medication management, and one-to-one support. Similarly, in 2011, Shattuck and colleagues<sup>14</sup> examined rates of parent-report post-high school service use among young adults with ASD. Results found that exiting high school was associated with a steep drop in service receipt, with 39.1% of youth receiving no medical, mental health, speech therapy, communication, or case management services. In addition to age, not receiving services was strongly associated with African-American ethnicity and living in a lower income household. While ID status was not directly examined, higher functional mental skills were associated with increased odds of not receiving services.

The experiences of individuals with ASD without ID may be unique since they are often ineligible for the same range of services as those with ID.<sup>15–17</sup> Adults with ASD without ID may also encounter greater social expectations and higher self-awareness as compared to individuals with ASD who have an ID,<sup>6</sup> further differentiating their service experiences. Despite this knowledge, only one study has examined the experience of using health care services from the perspective of adults with ASD without ID.<sup>18</sup> In this study, adults with ASD without ID reported higher odds of emergency department use and greater unmet health care needs related to physical health, mental health and prescription medications compared to adults without ASD. Adults with ASD without ID also reported lower satisfaction with patient-provider communication, general health care self-efficacy and chronic condition self-efficacy. While results would suggest that adults with ASD without ID are using *more* health services, they appear to feel *less* satisfied with them, and no studies have examined self-reported *barriers* to services. This is particularly concerning given the well-documented changes and challenges adults face as they transition from the pediatric to adult health care system where professionals who have the capacity and expertise to care for adults with ASD are limited.<sup>19,20</sup>

Provision and quality of health care for this population is a recognized priority in Canada,<sup>21,22</sup> the US<sup>23</sup> and the UK,<sup>24–26</sup> and the rising prevalence of ASD<sup>2</sup> will undoubtedly mean that many more adults will need specialized services in the future. Thus, it is critical that we understand the health service utilization patterns and health care experiences of adults with ASD without ID to effectively plan services for this population, and ensure their health care needs are met. With the exception of Nicolaidis et al.,<sup>18</sup> previous research has either focused on individuals with ID or included a mix of functioning levels,<sup>13,14</sup> but has not focused on the experiences of individuals with ASD without ID exclusively. It is important to understand the health care experiences reported *directly* from adults with ASD without ID themselves, rather than studying these issues indirectly from the perspectives of parents, caregivers or other family members.<sup>27</sup>

The present study addresses these gaps by examining a diverse range of medical and mental health services and supports, as well as adults' personal experiences accessing and using these services, barriers to service use, and reported unmet service needs tracked over 12–18 months. Finally, the current study considers the demographic and clinical factors associated with rates of service use, satisfaction with services, and barriers to health care.

## 2. Methods

### 2.1. Participants

Participants included 40 adults who self-reported a clinical diagnosis of Asperger Syndrome (AS) or ASD without ID (ages 18–61;  $M = 35.88$ ,  $SD = 11.70$ ). Participants were deemed eligible if they were at least 18 years old, reported to have received a diagnosis of AS or ASD without ID, had the capacity to self-report on their health history and service use, and completed the first and last study questionnaires across a 12–18 month period. ASD diagnosis was confirmed through the use of a standardized ASD self-report screening tool (Autism Spectrum Quotient; AQ).<sup>28</sup> To be included in the study, AQ scores had to exceed the recommended cut-off score of  $\geq 26$ .<sup>29</sup> Although 66 individuals completed the baseline survey, 14 individuals were excluded from the current analysis because they did not meet the recommended AQ cut-off score and an additional 12 adults did not complete the first and last surveys within the designated study time period.

### 2.2. Materials and procedures

Participants were recruited from across Ontario through flyers and websites of collaborating community agencies as well as through every local chapter of the provincial ASD organization. Efforts were made to reach individuals living in all regions of the province, including remote and rural settings where individuals may be marginalized economically or geographically. Of the 40 participants meeting eligibility criteria, 10% ( $n = 4$ ) resided in rural areas with fewer than 1000 inhabitants and a population density below 400 people per square kilometer, which is comparable to overall provincial rates.<sup>30</sup> In order to increase accessibility of the survey, participants had the option to complete a paper version that would be mailed to them, a telephone interview or online surveys. One participant completed the survey by telephone, and the remaining 39 adults completed the survey online. This research was approved by the university and hospital research ethics boards.

Participants completed the de-identified longitudinal survey tracking service utilization on a bi-monthly schedule. Participants provided baseline information (first survey) and completed six bi-monthly follow-up surveys. Some individuals took more time to complete the surveys, and data were only retained if the time between their first and final survey was no less than 12 months and no more than 18 months ( $M = 15.3$  months,  $SD = 1.3$  months). Participants were asked to respond to items based on services used since the last time they completed a survey. On average, participants completed 5.3 surveys ( $SD = 1.7$ ).

#### 2.2.1. Demographic variables

The following demographic variables were reported at baseline: age, gender, daily routines (structured or unstructured), race/ethnicity (white/Caucasian or non-white/non-Caucasian), marital status (married/living with partner or single), educational attainment, and neighborhood income. Individuals were classified as either having or not having 'structured' daytime activities based on their responses to the question: "What do you typically do during the day?" Response options included: Nothing, Day Program, School, Working/Volunteering/Job Training, or Other. Education level was dichotomized into individuals that had high education (college diploma or higher) or low education (some college or less). Neighborhood income was estimated based on the median income of the respondent's postal code.

#### 2.2.2. Clinical characteristics

The following clinical characteristics were reported at baseline:

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