# Market Segmentation as a Tool to Inform Health and Social Services Policy and Planning: The Case of Autism Spectrum Disorder and Intellectual Disability

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## Table 1. Step-by-step segmentation process

**Step 1: Determining segmentation dimensions**

*Diagnoses:* Because the DSM-5 (American Psychiatric Association 2013) defines ASD and ID as distinct conditions which can co-occur and which present with differing levels of support needs, the segmentation includes two dimensions, each with three categories: key diagnoses (ASD only, ASD with ID, ID only) and level of support (Low, Moderate, High).

*Stratification by age group:* As demonstrated by Westerinen and colleagues in Finland (Westerinen et al. 2017), applying average prevalence across age groups may be misleading and of little use; the results were therefore further stratified across age groups as follows: 0–7 years (in Quebec, there are particular services for this age range), 8–21 years and 22–74 years reflecting implications for varying services and support requirements. Given the paucity of data on older adults with ASD and/or ID and the reported reduced life expectancy of persons with ASD and/or ID (Bittles et al. 2002; Heslop et al. 2014), the group over 74 years of age was not considered.

**Step 2: Identifying the underlying Quebec populations by age**

The population size estimates by age for Quebec were obtained from Statistics Canada (2016). Data for five-year age categories were downloaded and adjusted using the 1-year values to align with the age categories of interest outlined in step 1 (e.g., 5–9 was changed to 5–7 and 8–9). Among the population considered (n = 7,683,414), 9.3% were 0–7 years of age, 15.7% were 8–21 years of age and 75% were 22–74 years of age.

**Step 3: Estimating the total number of Quebeckers with ASD by age group**

North American studies have reported increases in ASD prevalence since the 1980s (Coo et al. 2008; Ouellette-Kuntz et al. 2014; Noiseux 2014; Rice et al. 2010). Therefore, age-specific prevalence proportions were applied to the respective age categories up to age 30 using proportions reported by the Centers for Disease Control and Prevention (Baio et al. 2018; Baio 2014) among 8-year-olds for different birth cohorts. These prevalence statistics ranged from 0.67% for 20–30-year-olds to 1.46% for those under 10 years of age. Prevalence figures reported for the 1970s (0.4%; Heussler et al. 2001) and 1960s (0.04%; Lotter 1966) were applied to those in the 4th and 5th decade of life, respectively. The prevalence among 30–39-year-olds was estimated at 0.5% to reflect the expected trend across birth cohorts (i.e., the midpoint between 0.67% for 20–30-year-olds and 0.4% for 40–49-year-olds). In the absence of information regarding expected prevalence among those 60 years and over, the prevalence for 50-year-olds was gradually reduced across the remaining three age categories (e.g., from 0.03% among 60–64-year-olds to 0.01% among 70–74-year-olds; note that autism was first identified in 1943).

**Step 4: Estimating the total number of individuals with ID by age group**

The prevalence of ID has not been as extensively studied as the prevalence of ASD. Systematic reviews and meta analyses have consistently reported the prevalence of ID across a mixed population of children and adults to be roughly 1% (Maulik et al. 2011; McKenzie et al. 2016). However, this 1% is not distributed equally across all age groups; the prevalence is highest in childhood and adolescence and decreases steadily through each decade of adulthood (Ouellette-Kuntz et al. 2016). We applied published prevalence among cohorts of 8-year-olds (1991 to 2010) summarized by Van Naarden Braun and colleagues (2015) to relevant age categories as follows: 1.36% (the prevalence in 8-year-olds in 2010) to our population to age 7 in 2016 and 1.2% (the prevalence in 8-year-olds in 2000) to our population 8–19 years of age in 2016. Prevalence in adult age categories were obtained from Ouellette-Kuntz et al.'s (2016) analysis of Ontario health and social service data; these ranged from 0.5% among those 25–44 years to 0.32% among those 65–74 years of age. The prevalence estimates applied across adult age groups were as follows: 20–24: 0.94%; 25–44: 0.5%; 45–64: 0.43%; 65–74: 0.32%.

**Step 5: Distributing the population with ASD across levels of support need**

No population-based studies were identified that use objective measures of support need levels for individuals living with ASD. A US survey of over 967 parents of children 6–17 years of age with ASD indicated that 12% of parents rated their child's disability as severe, 37.5% rated the disability as moderate and 50.5% indicated the disability was mild (Zablotsky et al. 2015). In contrast, a smaller Canadian study relying on the Scales of Independent Behaviour-Revised (Brown et al. 2011), reported that among 97 children with ASD between the ages of 6 and 13 years, 27.8% had extensive or pervasive support needs, 48.5% had limited to frequent support needs and 23.7% had no to intermittent support needs. The values from these two studies were pooled to provide estimates of the proportion of individuals with ASD across low (48.1%), moderate (38.5%) and high (13.4%) support needs.

**Step 6: Estimating the number of individuals with ID by level of support**

According to the DSM-5, the ID population is expected to be distributed across four levels of severity as follows: 85% mild, 10% moderate, 3.5% severe, 1.5% profound based on IQ cut-offs (American Psychiatric Association 2013). However, level of functioning and related support needs are understood to be the result of both cognitive deficits and adaptive function. Because adaptive skills are age-dependent, the level of support would be expected to change with age. No population-level studies or studies on ID support level needs covering the age-span of interest were identified; however, having applied age-specific prevalence proportions (Step 4), some of the variability in numbers across support levels by age will have been captured. Because factors other than IQ, such as health and social problems, affect service needs, the distribution across support levels was further refined by using results from an Ontario study of a sample of 115 adults with ID requesting services which found that based on the Supports Intensity Scale, 43.5% had low (levels I and II), 33.9% had moderate (level III) and 22.6% had high (IV) support needs (H. Ouellette-Kuntz 2017, personal communication, 11 November). Recognizing that the latter may not be generalizable to the entire population with ID, information from the IQ distribution was used to adjust the allocation across support levels for both children and adults. A weighted average of the DSM-5 breakdown and the above-noted Ontario study results was applied; the DSM values were given a weight of 0.75 and the Ontario study estimates a weight of 0.25. The resulting estimates used across all age groups were: 75% low support, 16% moderate support and 9% high support.

**Step 7: Estimating the number of individuals with co-occurring ASD and ID**

Zablotsky et al. (2015) reported that the proportion of individuals with ASD (6 to 17 years) who also had ID varied by level of severity of ASD (ID was reported among 10% of mild, 29.7% of moderate, and 45% of severe cases of ASD). These were applied to the numbers of individuals with ASD across age categories. The derived figures for total number of individuals with ASD also having co-occurring ID and for total number of individuals with ID also having ASD were then cross-checked with extant publications.

**Step 8: Distributing population with co-occurring ASD and ID across levels of support need by age group**

In the absence of evidence, to distribute the number across levels of support, we assumed that the presence of both conditions would increase the level of support. We integrated that assumption and expert opinions for the 2014 McKinsey segmentation to apply the following breakdown estimated to have co-occurring ASD and ID across age categories: 15% low, 60% moderate and 25% high.

**Step 9: Estimating the number of individuals with ASD only and ID only and distributing these across levels of support need**

Because the number with ASD with ID was estimated as a proportion of the estimated numbers with ASD using findings from a study of children and adolescents (Zablotsky et al. 2015), the ASD-only estimates were derived mathematically by subtracting estimates for ASD with ID from the overall estimate for ASD for the age categories up to 21 years. For those 22 years and older, we took into account the historical views of adults with ASD as simply being a sub-group of those with ID and the resulting lack of applicable population-level data of co-occurrence in these older cohorts. We thus subtracted the numbers with both ASD and ID (Zablotsky et al. 2015) from the estimated number with ID (DSM-5) to identify the expected numbers in the ID-only subgroup across support levels.

**Step 10: Verification of face validity**

The face validity of the overall segmentation was examined by comparing some of the key findings to commonly cited prevalence statistics from the DSM-5 (American Psychiatric Association 2013) and the Centers for Disease Control and Prevention (Baio et al. 2018; Baio 2014). For example, our segmentation showed prevalence of ID and/or ASD at 1.2% versus the 2% cited in the DSM-5. Our lower estimate (0.76%) is only apparent in our adult segment (which is our largest segment) suggesting that the DSM-5 estimate may not reflect the effect of premature mortality. The prevalence of ASD among young children (0–7 years) in our Quebec segmentation is 1.47 % which is consistent with prevalence reported by the Centers for Disease Control and Prevention (Baio et al. 2018; Baio 2014) among 8-year-olds. The DSM-5 cites that 85% of individuals with ID have a mild ID. Our segmentation by level of support need similarly shows that 80% of individuals with ID only have low support needs. There is, however, a lesser proportion with low support needs in our segmentation if we include individuals both with and without co-occurring ASD (70%). This is coherent with the premise that fewer individuals having both ASD and ID should have low support needs than those with ID only.