Multiple clinicians independently coded the data for discussions, to quantitatively describe the results. Categories, which were created through consensus, Responses from completed surveys were coded into ASD. The survey asked families to reflect on their child with confirmed or suspected dual diagnosis DS-. The survey was distributed to 486 caregivers. The survey response rate was 35% (n=172), and of those, the survey completion rate was 39% (n=67). There were 67 survey entries, and 47 surveys were included—9 surveys were excluded as they only submitted demographic information, and 11 were excluded because the child was never formally diagnosed with ASD. Caregivers developed concerns about their child's development at an average age of 3.9 years. There was a mean 4.7-year gap between the age that families first noticed signs of autism and the age of diagnosis, which occurred on average at 8.5 years.

Most participants expressed their initial concerns to the child's primary care provider (PCP) (47%), or educators and therapeutic service providers (57%). Of respondents who expressed initial concerns to a PCP, 82% felt that the provider did not have the knowledge or experience required to address their concerns. The most commonly reported initial presenting concerns were stereotypic behaviors (53%), lack of interest in social relationships or poor shared attention (49%), expressive language deficits (40%), sensory sensitivity or defensiveness (29%), poor eye contact (27%), slower progress in developmental milestones (27%), mood or behavior abnormalities (24%), abnormal patterns of play (22%), and developmental regression (18%).

When asked about the most helpful interventions for their child, 37% of respondents mentioned Applied Behavioral Analysis (ABA therapy), and 35% listed other therapeutic services (including speech, physical, and occupational therapy). Respondents were divided when asked whether school was a helpful resource—only 51.3% felt that the school met their child's needs. Overall, caregivers noted both positive and negative effects of the dual diagnosis on their families. 38% of participants experienced feelings of isolation, but another 38% felt that their family unit became stronger and more empathetic through the process.

The incidence of autism spectrum disorder (ASD) is higher in children with Down syndrome (DS) than in the general population. Estimates range greatly from 5-39%, depending on the ascertainment and diagnostic criteria used. This suggests that children with DS are at least 3 times more likely to have ASD than children in the general population, where the estimated prevalence is 1.7%.

ASD is often diagnosed at a later age in patients with DS, if they are diagnosed at all. Until the late 1980s, it was believed that ASD is rare in individuals with DS. Their relative strength in social skills was thought to be protective against ASD. Further, shared symptomatology between DS and ASD can lead to diagnostic overshadowing and delays in diagnosis.

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