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Comparisons between Individuals with Autism Spectrum Disorders and Individuals with Down Syndrome in Adulthood

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Abstract

Differences between 70 adults with autism spectrum disorders (ASD) and intellectual disability and 70 age-matched adults with Down syndrome (DS) were examined on variables indicative of independence in adult life. Adults with ASD had less residential independence and social contact with friends, had more limited functional abilities and literacy, exhibited more behavior problems, had more unmet service needs, and received fewer services as compared to adults with DS. Reflecting these differences, adults with ASD were less likely to be classified as having high or moderate levels of independence in adult life as compared to adults with DS. Predictors of independence in adult life differed for adults with ASD as compared to adults with DS. Implications for service delivery are discussed.

Keywords

adults; autism spectrum disorders; Down syndrome; intellectual disabilities; outcome

As larger numbers of children with the diagnosis of autism spectrum disorders (ASD) exit the educational system and enter adulthood, it has become increasingly important to understand the course of this lifelong disorder. Information about the outcomes of adults with ASD and the challenges that they face in their transition to adulthood is central to service provision and policy planning. However, limited research has been conducted in this area, with the few studies that have examined adults with ASD generally reporting poor outcomes (Billstedt, Gillberg & Gillberg, 2005; Howlin, Goode, Hutton & Rutter, 2004; Piven, Harper, Palmer & Arndt, 1996). Despite evidence that ASD symptoms abate to some extent over time (Seltzer, Krauss, Shattuck, Orsmond, Swe & Lord, 2003; Shattuck et al., 2007), the majority of adults with ASD continue to exhibit significant impairments and difficulties with typical tasks of adulthood (e.g., employment, social relationships, residential independence; Howlin et al., 2004).

Previous descriptions of adults with ASD highlight their wide range of outcomes across different areas of adult functioning (e.g., Ballaban-Gil, Rapin, Tuchman & Shinnar, 1996; Eaves & Ho, 2008; Howlin et al., 2004). This work has also been influential in pointing out that these individuals continue to experience significant difficulties as adults, which has

underscored the need for intervention and public service programs aimed at improving adult outcomes. However, because studies of adults with ASD have focused primarily on within-group analyses (Seltzer et al., 2003; Billstedt et al., 2005), they are limited as far as the extent to which they can provide a relevant basis for comparison. To date, examinations of independence in adult life have presented outcomes in terms of what would be expected of a typical adult (Howlin et al., 2004), and little is known about how adults with ASD fare in comparison to their peers with other types of developmental disabilities. Independence in adult life is subjective, although several common goals are promoted by various government agencies and organizations (Luckasson et al., 2002; US Department of Health and Human Service, 2000). These goals include vocational and residential independence, having friends, and engaging in leisure activities. To be consistent with previous literature on outcomes in adults with ASD (Ballaban-Gil et al., 1996; Eaves & Ho, 2008; Howlin et al., 2004), for the purpose of this paper independence in adult life is defined by residential independence, social contact with friends, and vocational independence. Although it would be ideal if individuals with ASD could achieve the same independence as their typically developing peers, it is also important to know how adults with ASD compare to adults with non-ASD developmental disabilities.

Information about the specific areas in which adults with ASD differ relative to their peers with other developmental disabilities is useful both in terms of knowing how adults with ASD currently fare, as well as in guiding future service provision efforts. Previous research suggests that there may be a significant discrepancy between what many adults with ASD are capable of and how they perform or function (Howlin et al., 2004; Gerhardt & Holmes, 1997). Details about the strengths and weaknesses of adults with ASD in comparison to adults with non-ASD developmental disabilities would be beneficial in setting intervention goals and designing programs to reduce this discrepancy.

Similarly, limited research has been conducted on adult outcomes for individuals with Down syndrome (DS; Carr, 2008). Although much is known about the aging of adults with DS in regard to their health concerns, cognitive declines later in life, and life expectancy, only a little is known about what predicts outcomes for these individuals earlier in adulthood (Bittles, Bower, Hussain & Glasson, 2007; Bittles & Glasson, 2004; Esbensen, Seltzer & Krauss, 2008; Holland, 1999). Details about how adults with DS succeed in meeting the milestones of adulthood and what leads to better outcomes will be informative for transition planning and the provision of ongoing adult supports.

In the present investigation, we compare adults with ASD to adults with DS. In one of the few previous comparative studies of this type, Loveland and Kelley (1988) reported no differences in adaptive behavior between adolescents and young adults with ASD and peers with DS (ages 10-29). However, they did find age-related differences as well as group differences in adaptive behavior relative to intellectual functioning (Loveland & Kelley, 1988). Adaptive behavior was better among the older than younger individuals with DS, and was consistent with their intellectual functioning. In contrast, for individuals with ASD, their level of adaptive behavior was not found to be associated with age, and was more delayed relative to their level of intellectual functioning. This pattern of discrepancy between intellectual functioning and certain aspects of adult adaptive behavior for adults with ASD was also reported by Gerhardt and Holmes (1997), and may be an important impediment to achieving adult milestones (e.g., residential independence) for which adaptive behavior is important.

Although few studies have compared ASD and DS in adulthood, many studies have explored the differences between children with ASD and children with DS. Results have been overwhelmingly consistent in indicating that children with ASD tend to function more poorly than those with DS. Children with ASD have been found to have fewer adaptive skills

(Rodrigue et al., 1991), fewer social and communication skills (Bieberich & Morgan, 1998; Dawson, Meltzoff, Osterling, Rinaldi & Brown, 1998; O'Neill & Happé, 2000; Sigman & Ruskin, 1999), more behavior problems (Eisenhower, Baker & Blacher, 2005), more sleep problems (Cotton & Richdale, 2006), and less behavioral flexibility (Didden et al., 2008) than children with DS. Children with ASD have also been found to exhibit more impaired interactions with their parents and siblings than children with DS (Hoppes & Harris, 1990; Kasari & Sigman, 1997).

Because most comparative work in this area has been limited to children, it is unknown whether a similar pattern of poorer outcomes persists into adulthood for individuals with ASD as compared to individuals with DS. As individuals with ASD and DS age beyond childhood and young adulthood, divergent life course trajectories are suggested by within-group studies. Among adults with ASD, the severity of symptoms tends to abate to some extent with age and skills improve (Seltzer et al., 2003; Shattuck et al., 2007), whereas the acquisition of skills among adults with DS begins to level off and functional abilities decline in midlife (Esbensen, Seltzer & Krauss, 2008; Zigman et al., 1987, 1995, 2002). Thus, it is possible that the gap evidenced in studies of children with ASD compared to children with DS may narrow in adulthood. Alternatively, it is possible that adults with ASD continue to exhibit a profile of relative poorer outcomes compared to adults with DS, and that the difficulties they experience in adulthood are above and beyond what would generally be expected given their intellectual functioning and symptoms.

This paper builds on previous research by examining the relative skill profiles of adults with ASD and adults with DS. For this analysis, we address three primary research aims. First, we examine whether adults with ASD differ from adults with DS with respect to three core domains of independence in adult life as defined by previous research: residential independence, social contact with friends, and vocational independence (Ballaban-Gil et al., 1996; Eaves & Ho, 2008; Howlin et al., 2004), and on an overall composite measure of independence in adult life based on these three core domains. To increase the comparability of the two groups of adults in intellectual functioning, only adults with ASD who also had intellectual disability (ID) were included in these analyses. Second, we address whether adults with ASD differ from adults with DS with respect to other variables that may facilitate adult functioning. We examine variables that are known to differ between children with ASD and DS, including functional abilities, literacy, and behavior problems, as well as variables that are pertinent to adulthood, such as health and service usage. And third, we assess the extent to which these other variables (health, functional abilities, literacy, behavior problems, and service use) differentially predict the overall composite measure of independence in adult life for adults with ASD versus adults with DS.

Methods

Sample and Procedures

Participants were selected from an ongoing study of 406 individuals with ASD (Seltzer et al., 2003) and a completed study of 169 individuals with DS (Krauss & Seltzer, 1999). In both studies, the maternal respondent was interviewed at 18 month intervals regarding her son or daughter's health, behavior problems, functional abilities, and daily activities. In both studies, about half of the families lived in Massachusetts and the other half in Wisconsin. The criteria for inclusion in the DS study were that the mother was between the ages of 55 and 85, and the son or daughter lived at home with her at the beginning of the study. The criteria for inclusion in the ASD study were that the son or daughter with ASD was age 10 or older, had received an independent diagnosis of ASD (Autistic Disorder, Asperger Disorder, or PDD-NOS) from an educational or health professional, and had a research-administered Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter & Le Couteur, 1994) profile consistent with the

diagnosis. Unlike the inclusion criteria for the DS study, individuals with ASD were selected for the ASD study either if they lived with their families or if they lived in non-family settings. Families in both studies volunteered to participate.

The analyses reported here are based on data collected at the second round of data collection (in 2000-2001) from the ASD study and at the seventh round of data collection (in 1997-1998) from the DS study. These points of data collection were selected because they were close to each other in time, which was intended to minimize the influence of the economic, policy, and other contextual factors that may differ over time. Participants from both studies who were selected for the present analysis were age 22 and older and also had a diagnosis of ID.

Intellectual disability status for adults with DS was confirmed by a review of state and agency records and by the results of IQ testing using the Stanford-Binet 4th Edition (SB:FE; Thorndike, Hagen & Sattler, 1986). Intellectual disability status for adults with ASD was determined using a variety of sources of information (as described in Smith, Greenberg, Seltzer & Hong, 2008) including IQ testing with the Wide Range Intelligence Test (WRIT; Glutting, Adams & Sheslow, 2000), adaptive behavior assessment with the Vineland Screener (Sparrow, Carter & Cicchetti, 1993), and a review of available records (standardized assessments, parent report of prior diagnoses, intellectual functioning, and adaptive behavior; and clinical and school records).

To select the sample for the present analysis, adults with ASD were matched on age within 4-year age intervals with adults with DS. Age matching resulted in a final sample of 70 adults with ASD and 70 adults with DS. In both groups, the adults averaged about 37 years of age, and were primarily male and Caucasian (see Table 1). About half of adults with ASD had mild or moderate ID (52.8%), whereas the majority of adults with DS had mild or moderate ID (72.8%). There were no differences between adults with ASD and adults with DS with respect to age, $t(138) = .02, p = .98$, gender, $\chi^2(1) = 0.13, p = .72$, or ethnicity, $\chi^2(4) = 3.39, p = .49$. Compared to adults with DS, adults with ASD were significantly more likely to live away from the family home, $\chi^2(1) = 35.18, p < .001$, to have a lower level of ID, $\chi^2(3) = 11.41, p < .01$, and their mothers had higher levels of education, $\chi^2(3) = 12.29, p < .01$. Therefore, maternal education, residential status, and level of ID of the son or daughter were controlled in the analyses.

Measures

Residential arrangements—Mothers reported on their adult sons' or daughters' current living situation. Categories of living situations were: living independently, living semi-independently, co-residence with family or other relatives, living in a community residence, and living in a hospital or institution.

Social contact with friends—Mothers reported on their adult sons' or daughters' social and recreational activities on a modified version of a measure developed for the National Survey of Families and Households (Bumpass & Sweet, 1987). In both studies, mothers rated the frequency of participation of the son or daughter in socializing with friends or neighbors as (0) less than yearly or never, (1) about 1-10 times per year, (2) about once per month, (3) about once per week, and (4) several times a week.

Vocational activities—Mothers reported on whether (1) or not (0) the adult son or daughter participated in any of the following vocational activities on a regular basis: day activity or day habilitation program, sheltered workshop, supported employment, competitive employment, or volunteer work. Participants were also categorized as having (1) any vocational activity or (0) no vocational activity. Participants who only did volunteer work were categorized as having no vocational activity.

Overall composite of independence in adult life—A composite measure of independence in adult life was created, modified from one developed by Howlin and colleagues (2004). This composite was a sum of ratings in the core domains of residential independence, social contact with friends, and vocational independence. *Residential independence* ratings were (0) living in a hospital or institution, (1) living in a community residence, (2) living with family or other relatives, (3) living semi-independently, and (4) living independently. *Social contact with friends* ratings were extracted from maternal reports of social and recreational activities. It was rated as (0) never visiting with friends or seeing them less than yearly, (1) seeing friends less than once per month, (2) seeing friends at least once per month, (3) seeing friends at least once per week, and (4) seeing friends more than once per week. *Vocational independence* ratings were (0) volunteer work or no formal day activity, (1) day habilitation program, (2) sheltered employment, (3) supported employment, and (4) competitive employment. To create a composite measure, ratings on these three core domains were summed and categorized reflecting: (0-2) “very low”, (3-5) “low”, (6-8) “moderate”, (9-11) “high”, and (12) “very high” levels of independence in adult life.

Health—In both studies, health was measured using a maternal rating of her son or daughter's current health status (1 = poor, 2 = fair, 3 = good, 4 = excellent). In a meta-analysis of 27 studies, such global ratings of health have been found to be valid measures of morbidity, net of sociodemographic factors known to affect health (Idler & Benyamini, 1997).

Functional abilities—Functional abilities were measured in both studies using an 18-item scale that covered skills in the areas of housework, personal care, and meal related activities. This measure of functional skills was based on a revised version of the Barthel Index (Mahoney & Barthel, 1965) to measure personal and instrumental activities of daily living appropriate for adults with ID (Seltzer, Ivry & Litchfield, 1987). Each item was rated on a 3-point scale of independence (0 = does not do task at all, 1 = does task with help, 2 = does task independently), and averaged for a total score. Our measure of functional abilities correlates .82 with the Vineland Screener scale composite (Sparrow, Carter & Cicchetti, 1993) in the sample of adults with ASD, the group for whom the Vineland Screener was available.

Literacy—Mothers in both studies reported on their adult son's or daughter's ability to read and write. Reading skills were rated as (0) cannot read, (1) reads a few words, (2) reads simple sentences, and (3) reads paragraphs. Writing skills were rated as (0) cannot write, (1) writes a few words (including name), (2) writes simple sentences, and (3) writes paragraphs. These measures of reading and writing skills correlate significantly with the verbal IQ measure of the WRIT ($r = .57, .67$, respectively, both $p < .001$), with the Communication domain of Vineland Screener ($r = .81, .81$, respectively, both $p < .001$), and with each other ($r = .80, p < .001$). As reading and writing were strongly inter-correlated, we created a ‘literacy’ variable based on the summed score of reading and writing skills.

Behavior problems—Behavior problems were assessed in both studies using the Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman & Hill, 1996). This measure captures the frequency and severity of eight types of behavior problems, providing a Generalized Maladaptive Index. Individual problem behaviors are scored as present or absent. Index scores provide ratings of the seriousness of the problem behavior as normal (90-110), marginally serious (111-120), moderately serious (121-130), serious (131-140) or very serious (141 or above). Reliability and validity are excellent for the maladaptive behavior subscale (Bruininks, Hill, Weatherman & Woodcock, 1986).

Service usage—Mothers also reported on the following nine services available to the adult son or daughter at the time of the data collection: physical therapy, occupational therapy, speech

and language therapy, psychological or psychiatric services, personal care assistance, agency sponsored recreational or social activities, transportation services, income support, and vocational services. Mothers in both studies rated whether each service was received, and if not, whether it was an area of unmet need. The sum of the number of services rated within each of these two categories was calculated.

Method of Data Analysis

To address the first research aim, which concerned differences between adults with ASD and DS in the core domains of independence in adult life, multivariate analyses of covariance (MANCOVAs) were used to contrast the two groups with respect to residential independence, social contact with friends, and vocational independence. Maternal education and level of ID were controlled in all analyses. Residential placement (co-residing or living away from the family home) was controlled in the analyses of social contact with friends and vocational independence. Where the MANCOVAs indicated significant differences, subsequent analyses of covariance (ANCOVAs) were used to test for differences between adults with ASD and adults with DS on the individual measures within each domain. Because of the dichotomous nature of the outcome variables, logistic regression is the preferred statistical analysis. We ran these analyses using logistic regression, and the findings were identical to the findings from the ANCOVA approach (data available from the first author). However, we present the ANCOVA findings as they nicely illustrate the group means. A two-tailed chi-square test was used to assess differences in the overall independence in adult life composite rankings between adults with ASD and adults with DS.

To address the second research aim, which concerned differences between adults with ASD and adults with DS in health, functional abilities, literacy, behavior problems, and service usage, we again used MANCOVA. Residential status, level of ID, and maternal education were controlled in this analysis. Where a significant difference was found with the MANCOVA, subsequent ANCOVAs were used to test for differences between adults with ASD and adults with DS on the individual variables.

To address our third research aim which concerned the factors that predicted the overall composite of independence in adult life, parallel multiple regressions were used for adults with ASD and again for adults with DS. These regressions tested if the variables in our second aim (health, functional abilities, literacy, behavior problems, and service usage) predicted the composite of overall independence in adult life. Because the measures of receiving services and unmet service needs were not independent of each other, we excluded the unmet service needs from the regression analysis, including only the number of services received (Model 1). Additionally, in an effort to explore whether specific services have a differential association with outcomes, we ran the regression models again, replacing the number of services received with the individual services as predictors (physical therapy, occupational therapy, speech and language therapy, psychological or psychiatric services, personal care assistance, agency sponsored recreational or social activities, transportation services, and income support). Vocational services were not included as a predictor variable because of its overlap with the outcome of independence in adult life. Each service was tested in a separate exploratory model to determine which significantly contributed to the prediction of independence in adult life. Individual services that significantly contributed to the prediction of independence in adult life were entered into Model 2, along with health, functional abilities, literacy, and behavior problems. Residential status, level of ID, and maternal education were controlled in this analysis.

Results

Comparing Adults with ASD to Adults with DS on Measures of Independence in Adult Life

Our first research aim addressed differences between adults with ASD and adults with DS on three core domains of independence in adult life, namely residential independence, social contact with friends, and vocational independence. Because of small sample sizes within cells, living independently ($n=1$) or in a hospital or institution ($n=3$) were excluded from the MANCOVA for residential independence. MANCOVAs revealed significant group differences with respect to residential independence, $F(3,131) = 13.49, p < .001$, and social contact with friends, $F(4,116) = 4.21, p < .01$, but not with respect to vocational independence, $F(4,125) = 1.29, p = .28$ (see Table 2).

Within the domain of *residential independence*, follow-up ANCOVAs revealed that adults with ASD were less likely to live with family, $F(1,133) = 39.89, p < .001$, and were more likely to live in a community residence, $F(1,133) = 30.02, p < .001$, than adults with DS (see Table 2).

Within the domain of *social contact with friends*, follow-up ANCOVAs revealed that adults with ASD had less frequent social contact with friends than adults with DS. A significantly smaller percentage of adults with ASD spent time with their friends and neighbors several times a week, $F(1,119) = 15.80, p < .001$, as compared to adults with DS (see Table 2). Only 8% of the adults with ASD visited with friends and neighbors several times a week, as compared to a quarter of adults with DS.

Adults with ASD significantly differed from adults with DS with respect to the composite measure of *overall independence in adult life*, $\chi^2(4) = 9.79, p < .05$ (see Table 3). Whereas 62.3% of adults with DS were rated as having a “moderate” or “high” level of independence in adult life, only 37.4% of adults with ASD were rated comparably. It was noteworthy that none of the adults with DS and only one adult with ASD had a “very high” level of independence in adult life (lived independently, had a competitive job, and visited with friends and neighbors several times a week).

Comparing Adults with ASD to Adults with DS on Factors Facilitative of Independence in Adult Life

Our second research aim addressed differences between adults with ASD and adults with DS on key variables that might facilitate independence in adult life: health, functional abilities, literacy, behavior problems, and service use. The overall MANCOVA revealed significant group differences between the adults with ASD and the adults with DS, $F(6,115) = 4.72, p < .001$ (see Table 4). Follow-up ANCOVAs revealed significant group differences in functional abilities, $F(1,120) = 7.97, p < .01$, literacy, $F(1,120) = 4.39, p < .05$, behavior problems $F(1,120) = 10.21, p < .01$, the number of unmet service needs, $F(1,120) = 12.12, p < .001$, and the number of services received, $F(1,120) = 4.01, p < .05$. Adults with ASD were more impaired in their total functional abilities, had poorer literacy skills, exhibited more behavior problems, had more unmet service needs, and received more services than adults with DS. However, the two groups did not differ with regard to health, $F(1,120) = 0.02, p = .88$. Both adults with ASD and adults with DS were in similarly good health.

Predictors of Overall Independence in Adult Life

Our third research aim addressed whether variables that might facilitate independence in adult life (health, functional abilities, literacy, behavior problems, and the number of services received) in fact predicted the composite of independence in adult life for adults with ASD and adults with DS. We initially tested the models including age as a predictor variable because of

the findings of Loveland and Kelley (1988). However, as it did not contribute to the models, we omitted age from our analyses.

Among adults with DS, 41% of the variance in the composite of independence in adult life was accounted for by the variables included in Model 1 (see Table 5, DS Model 1). Having better functional abilities, $\beta = .39, p < .01$, and receiving a greater number of services, $\beta = .31, p < .01$, were both significant predictors of better independence in adult life outcomes for adults with DS. As noted earlier, in preliminary analyses, we examined which individual services predicted independence in adult life. For adults with DS, three services were significant predictors: speech and language therapy, recreational services, and transportation services. When we replaced the total number of services received with these three individual services, we found that this model now accounted for 52% of the variance (see Table 5, DS Model 2). In addition to having better functional abilities, $\beta = .39, p < .05$, receiving speech and language therapy, $\beta = .22, p < .05$, recreational services, $\beta = .24, p < .05$, and transportation services, $\beta = .22, p < .05$, were all significant predictors of better independence in adult life outcomes for adults with DS.

Among adults with ASD, health, functional abilities, literacy, behavior problems and the number of services received accounted for 21% of the variance in the composite of independence in adult life (see Table 5, ASD Model 1). The only significant predictor was having better functional abilities, $\beta = .39, p < .05$. When we replaced the total number of services received with the individual service that, in preliminary analyses, had a significant contribution to independence in adult life for sample members with ASD, we found that this model now accounted for 30% of the variance (see Table 5, ASD Model 2). In Model 2, having better functional abilities, $\beta = .39, p < .05$ and *not* receiving psychological or psychiatric services, $\beta = -.34, p < .01$, significantly predicted better independence in adult life outcomes for adults with ASD.

Thus, for both adults with DS and adults with ASD, having better functional abilities was related to better adult outcomes. Receipt of services played a significant role in predicting better adult outcomes for adults with DS. Specifically, receiving particular services (speech/language, recreational services, and transportation) was predictive of better overall adult outcomes. On the other hand, receiving services was not related to better outcomes for adults with ASD. In fact, having a better outcome was related to *not* receiving (and by implication, not needing) psychological services.

For descriptive purposes, Table 6 presents the percentage of adults with DS and the percentage of adults with ASD who received each of the nine types of services that were assessed. We also present the percentage of adults who did not receive but needed each service. Adults with ASD received significantly more psychological or psychiatric services and more personal care assistance than adults with DS, whereas adults with DS received significantly more recreational services, vocational services, and income support than adults with ASD. Adults with ASD had a significantly greater unmet need for occupational therapy, speech and language therapy, and recreational services than adults with DS.

Discussion

Our study extended comparisons of individuals with ASD and DS into adulthood and showed that, relative to adults with DS, adults with ASD who also had ID continue to show the pattern of poorer outcomes that past research documented as evident during childhood. Although the two groups were comparable with respect to achieving vocational independence, adults with ASD and comorbid ID were living in less independent residential settings and had less contact with friends and neighbors than adults with DS, two core components of independence in adult

life (Howlin et al., 2004). Adults with ASD were also found to have lower ratings of overall independence in adult life than adults with DS. Only 37.4% of adults with ASD were rated as having a moderate or high level of independence in adult life, compared to 62.3% of adults with DS. Impairments in social and communication in adults with ASD may be contributing to their poorer outcomes in contact with friends and neighbors. However, it should be noted that adults with DS and adults with ASD were comparable in having infrequent contact with friends and neighbors. Thus, the poorer outcome on this component of independence in adult life cannot fully be accounted for by impairments associated with the core features of ASD.

In addition to having poorer overall adult outcomes as compared to adults with DS, adults with ASD were also more impaired in other variables associated with adult functioning. Adults with ASD were less able to carry out typical tasks of daily living, had poorer literacy skills, exhibited more behavior problems, received fewer services, and had more unmet service needs than adults with DS, even when level of ID was controlled. Our results suggest that the gap between individuals with ASD and DS observed in childhood does not narrow with age, but it instead persists into adulthood, and that the pattern of behavior problem and symptom abatement observed in adults with ASD (Shattuck et al., 2007) is not so prominent as to overcome existing group differences with adults with DS.

There were clear differences between the “average” adult with ASD and the “average” adult with DS in our sample. The average adult with ASD lived in a community residence, visited with friends less frequently than once a month (i.e., about one to ten times per year), and participated in a sheltered workshop or a day habilitation program. He or she was in good health, needed assistance to do most activities of daily living, was able to read and write only a few words, and exhibited at least three different types of problem behaviors (most commonly an unusual habit, withdrawn behaviors, and self-injurious behaviors). This average individual with ASD received more than three services (most frequently income support, psychological or psychiatric services, and transportation services) and had one unmet service need.

In comparison, the average adult with DS lived at home with his or her parents, visited with friends about once a month, and worked in a sheltered workshop, a profile consistent with the findings of other studies (Carr, 2008). He or she was in good to excellent health, was independent or needed only partial assistance on most daily living tasks, was able to read and write a few words or sentences, and exhibited only one type of problem behavior (most commonly an unusual habit). This average adult with DS received more than three services (most frequently income support, vocational services, and agency sponsored recreational or social activities) and had less than one unmet service need.

Although adults with DS have fewer impairments than adults with ASD, it should be noted that they still have some limitations. No individual with DS met the criteria for a very high level of independence in adult life, namely living independently, seeing their friends several times a week and working in competitive employment. Furthermore, about a third of the adults with DS never visited with friends or did so only once in the past year, and 15% had no vocational activity.

Our findings also indicate that the factors that are associated with independence in adult life in individuals with DS differ from those associated with independence among individuals with ASD. Functional abilities were related to better outcomes for both adults with ASD and DS, whereas receiving more services (speech and language, recreational, transportation) were related to better outcomes only for adults with DS. This difference is noteworthy, as adults with ASD were less likely to receive recreational services, and more likely to be in need of recreational services and speech and language therapy compared to adults with DS.

Another predictor of overall independence among adults with ASD was *not* receiving psychological or psychiatric services. Our findings suggest that adults with ASD not receiving psychological or psychiatric services are more likely to have better adult outcomes. Comorbidity of psychological disorders among individuals with ASD has been a relatively under-studied area until recently (Tsakanikos, Costello, Holt, Bouras, Sturmey & Newton, 2006). Early indications suggest that the prevalence of psychopathology among adults with ASD is no different from their peers with ID (Melville et al., 2008; Tsakanikos et al., 2006), yet over 60% of adults with ASD in our sample were receiving psychological or psychiatric services (versus 19% of adults with DS). It will be important for future research to examine the best ways to assess psychological and psychiatric needs among adults with ASD so that appropriate interventions can be put in place. Identifying the presence of comorbid behavior problems or psychological disorders in adolescents and young adults with ASD prior to exiting the school system and leaving the family home may be the best way to target services to this population and to minimize the long-term impact of these disorders on overall independence in adult life.

It was surprising that behavior problems did not emerge as a significant predictor of independence in adult life in our model. In examining this finding in more detail, we found that behavior problems were inversely correlated with residential independence, vocational independence and overall independence in adult life on a bivariate level ($r = -.18, -.23, -.28$ respectively, all $p < .05$). However, in the regression model, behavior problems did not predict independence in adult life beyond functional abilities and service use. This suggests that for both adults with ASD and DS, adaptive behaviors may be more strongly related to independence in adult life than maladaptive behaviors. However, this finding warrants replication in future research and thus should be interpreted cautiously.

A major strength of this study is that we were able to assess the lives of adults with ASD in comparison to a group of individuals with another type of developmental disability. In addition to the difference in diagnostic status, however, there were also other differences between our samples that resulted from the fact that they were initially recruited to participate in different studies. All of the individuals with DS were required to be co-residing with their families at the time that the study began, which could have contributed to some of the differences seen between the groups. Indeed, adults who lived with their families were more likely to be in need of services and receive fewer services than adults living in community residences. Although we controlled for residential status whenever possible, we were not able to do so in the independence in adult life analyses, since one of the components of independence in adult life was residential status. Similarly, due to non-independence, we were unable to account for the complex relationship between services received and unmet need for services in predicting adult outcomes, as questions about unmet needs are asked only when the particular service was not received. Other sample limitations included the fact that most of the families were Caucasian and that they all volunteered to participate. Thus, these families may not be entirely representative of other families with adult children with ASD or DS. Furthermore, because all of the adults with ASD also had ID, these findings may not be fully applicable to adults with ASD with average intelligence. Finally, although we controlled for level of ID, the fact that adults with ASD had lower levels of ID may have contributed to their poorer outcomes in unknown ways.

Even in comparison to adults with significant disabilities, the life skills of adults with ASD are severely lacking. A primary goal of service provision efforts should be to elevate the skills and activities of adults with ASD to be more commensurate with those of adults with other types of developmental disabilities. While a person's level of cognitive ability may be less malleable, especially in adulthood, it is certainly within our grasp as service providers to try to improve a person's level of functional abilities. Greater deficits in functional abilities, which are first

apparent in comparative studies of children with ASD, may have cumulative effects over the life-course that ultimately limit the independence of adults with ASD. Additionally, ASD-related social and communication impairments may impact relative rates of functional skill acquisition and negatively influence the trajectory of skill development in individuals with ASD. Investigations are needed to determine why children and adults with ASD do not appear to benefit from the same services as individuals with non-ASD developmental disabilities so that new, more effective methods of service delivery can be developed for them.

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Table 1

Demographics of adults with DS and adults with ASD and their respondents.

	DS (n=70)	ASD (n=70)
<u>Age</u>		
M (SD)	37.6 (7.0)	37.7 (7.5)
Range	24-52	22-53
22-30	14.3%	18.6%
31-40	48.6%	48.6%
40 and older	37.1%	32.9%
<u>Gender</u>		
Male	65.7%	68.6%
<u>Ethnicity</u>		
Caucasian	97.1%	94.2%
<u>Level of ID</u>		
Mild	28.6%	25.7%
Moderate	50.0%	27.1%
Severe	17.1%	35.7%
Profound	2.9%	8.6%
Unknown	1.4%	2.9%
<u>Residence</u>		
Residence outside the family home	21.4%	71.4%
<u>Maternal education</u>		
Less than high school	22.9%	4.3%
High school	37.1%	37.1%
Some college	21.4%	24.3%
College graduate or more	18.6%	34.3%

Table 2

Means and standard deviations for adults with DS and adults with ASD on the core domains of independence in adult life.

Variables	DS	ASD	F-statistic ^d
	M (SD)	M (SD)	
<u>Residential independence</u> ^a			$F(3,131) = 13.49^{***}$
Living independently ^b	.00 (.00)	.01 (.12)	
Living semi-independently	.06 (.24)	.09 (.29)	$F(1,133) = 0.86$
Living with family or other relatives	.78 (.42)	.29 (.46)	$F(1,133) = 39.89^{***}$
Living in a community residence	.14 (.35)	.57 (.50)	$F(1,133) = 30.02^{***}$
Living in a hospital or institution ^b	.01 (.12)	.03 (.17)	
<u>Social contact with friends</u> ^{a,c}			$F(4,116) = 4.21^{**}$
Several times a week	.25 (.44)	.08 (.27)	$F(1,119) = 15.80^{***}$
About once per week	.22 (.42)	.19 (.39)	$F(1,119) = 0.04$
About once per month	.13 (.34)	.14 (.35)	$F(1,119) = 0.57$
About 1-10 times per year	.10 (.30)	.16 (.37)	$F(1,119) = 0.77$
Less than yearly or never	.30 (.46)	.44 (.50)	$F(1,119) = 3.36$
<u>Vocational independence</u> ^{a,c}			$F(4,125) = 1.29$
Competitive employment	.13 (0.34)	.06 (0.24)	
Supported employment	.19 (0.40)	.29 (0.46)	
Sheltered workshop	.40 (0.49)	.25 (0.43)	
Day habilitation	.13 (0.34)	.32 (0.47)	
Volunteer work or no vocational activity	.15 (.36)	.08 (0.27)	

* $p < .05$,

** $p < .01$,

*** $p < .001$

^a Analysis controlled for maternal education and level of ID.

^b These variables were not entered in the MANCOVA or ANCOVAs due to small cell sizes.

^c Analyses controlled for residential status (coresiding or living away from the family home).

^d The degrees of freedom differed between the MANOVAs for the three core domains of independence in adult life due to missing data on individual measures within each of the core domains.

Table 3

Percentage of adults with DS and adults with ASD functioning at different levels of the composite measure of independence in adult life.

Level of overall independence in adult life	DS	ASD
Very high	0.0%	1.5%
High	9.8%	9.0%
Moderate	52.5%	28.4%
Low	31.1%	44.8%
Very low	6.6%	16.4%

Table 4

Means and standard deviations for adults with DS and adults with ASD on other variables facilitating independence in adult life ^a.

Variables	DS	ASD	F-statistic
	M (SD)	M (SD)	
<u>Variables facilitating independence in adult life</u>			$F(6,115) = 4.72^{***}$
Current health	3.29 (0.64)	3.20 (0.68)	$F(1,120) = .02$
Total functional abilities	1.43 (0.45)	1.16 (0.41)	$F(1,120) = 7.97^{**}$
Literacy	3.04 (2.05)	1.98 (2.12)	$F(1,120) = 4.39^*$
Generalized maladaptive behaviors	103.29 (4.88)	108.21 (6.84)	$F(1,120) = 10.21^{**}$
Number of unmet service needs	0.69 (1.07)	1.47 (1.67)	$F(1,120) = 12.21^{***}$
Number of services received	3.61 (1.53)	3.58 (1.89)	$F(1,120) = 4.01^*$

*
 $p < .05$,

**
 $p < .01$,

 $p < .001$

^a Analyses controlled for maternal education, level of ID, and residential status (coresiding or living away from the family home).

Table 5

Regression analysis predicting the composite measure of independence in adult life in adults with DS and adults with ASD.

	DS		ASD	
	Model 1 (n=59)	Model 2 (n=59)	Model 1 (n=59)	Model 2 (n=59)
Level of ID	.04	.06	.11	.12
Maternal education	-.06	-.04	-.04	-.06
Current health	.04	.04	.17	.22
Total functional abilities	.39**	.31*	.39*	.39*
Literacy	.26	.27	-.13	-.09
Generalized maladaptive behaviors	-.01	.01	-.05	-.02
Number of services received	.31**		-.12	
Speech and language therapy		.22*		
Psychological or psychiatric services				-.34**
Recreational services		.24*		
Transportation services		.22*		
R ²	.41	.52	.21	.30

*
 $p < .05$,

**
 $p < .01$,

 $p < .001$

Table 6

Percentage of adults with DS (n=67) and adults with ASD (n=69) receiving or in need of each individual service.

	Received service			Unmet service need		
	DS	ASD	$\chi^2(1)$	DS	ASD	$\chi^2(1)$
Physical therapy	7.5%	5.9%	0.14	7.5%	14.7%	1.79
Occupational therapy	7.5%	14.9%	1.88	3.0%	29.9%	17.62***
Speech and language therapy	9.0%	8.8%	0.00	17.9%	36.8%	6.03*
Psychological or psychiatric services	19.4%	63.2%	26.71***	3.0%	10.3%	2.90
Personal care assistance	14.9%	33.3%	6.27*	4.5%	4.3%	0.00
Recreational services	71.6%	46.4%	8.96**	13.4%	29.0%	4.90*
Transportation services	65.7%	59.4%	0.57	10.4%	8.7%	0.12
Income support	97.0%	82.6%	7.64**	0.0%	4.3%	2.98
Vocational services	77.6%	44.8%	15.21***	9.0%	16.4%	1.68

*
 $p < .05$,

**
 $p < .01$,

 $p < .001$