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# Services for Adults with an Autism Spectrum Disorder

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In Review

## Services for Adults With an Autism Spectrum Disorder

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The need for useful evidence about services is increasing as larger numbers of children identified with an autism spectrum disorder (ASD) age toward adulthood. The objective of this review was to characterize the topical and methodological aspects of research on services for supporting success in work, education, and social participation among adults with an ASD and to propose recommendations for moving this area of research forward. We reviewed the literature published in English from 2000 to 2010 and found that the evidence base about services for adults with an ASD is underdeveloped and can be considered a field of inquiry that is relatively unformed. Extant research does not reflect the demographic or impairment heterogeneity of the population, the range of services that adults with autism require to function with purposeful lives in the community, and the need for coordination across service systems and sectors. Future studies must examine issues related to cost and efficiency, given the broader sociopolitical and economic context of service provision. Further, future research needs to consider how demographic and impairment heterogeneity have implications for building an evidence base that will have greater external validity.



Le besoin de données probantes utiles au sujet des services augmente car un plus grand nombre d'enfants identifiés comme ayant un trouble du spectre de l'autisme (TSA) approchent de l'âge adulte. L'objectif de cette étude était de caractériser les aspects thérapeutiques et méthodologiques de la recherche sur les services de soutien de la réussite au travail, aux études et en participation sociale chez les adultes souffrant d'un TSA, et de proposer des recommandations pour faire avancer ce domaine de la recherche. Nous avons passé en revue la littérature publiée en anglais de 2000 à 2010, et constaté que les données probantes sur les services pour les adultes souffrant d'un TSA sont sous-développées et peuvent être considérées comme étant un domaine de recherche relativement informe. La recherche existante ne reflète pas l'hétérogénéité démographique ou des déficiences de la population, la gamme des services dont ont besoin les adultes souffrant d'autisme pour fonctionner et mener des vies utiles dans la communauté, et le besoin de coordination des secteurs et systèmes de services. Les prochaines études doivent examiner les questions liées aux coûts et à l'efficacité, étant donné le contexte sociopolitique et économique élargi de la prestation de services. En outre, la recherche future doit prendre en compte la façon dont l'hétérogénéité démographique et des déficiences influe sur l'établissement d'une base de données probantes qui aurait une plus grande validité externe.

The identified prevalence of ASDs has been increasing steadily for more than a decade.<sup>1</sup> Given current estimates of prevalence (1 per 110) and population figures, we estimate about 4900 Canadian and 48 500 US teenagers with an ASD reach their 18th birthday each year. Most of a typical lifetime is spent in adulthood, yet most autism research is focused on early childhood.<sup>2,3</sup> As more children identified with an ASD age toward adulthood, there is an increasing need for research on services for the growing population of adults with an ASD.

Several recent efforts reviewed research on services for adults with an ASD. The UK National Audit Office concluded that this population uses a wide variety of services but specific data about service access, cost, and effectiveness are sparse.<sup>4</sup> A review of evidence rated 3 out of 9 types of interventions for adults with an ASD as evidence-based: supported employment, structured teaching, and behaviour modification.<sup>5</sup> A report on the state of services for adults with an ASD in the United States noted high unemployment levels, a tendency for families to be primary

care providers through adulthood, high staff turnover rates on the front lines of service provision, inadequate transition planning during the high school years, and pervasive gaps between the level of need for services and those currently available.<sup>6</sup> A 2011 US government document proposed that research on services for adults with an ASD should focus on needs assessment, care coordination across service delivery systems, and models for providing lifelong supports in community settings.<sup>7</sup> These reports have made significant contributions to the discussion about what research is needed. However, there are still gaps in this dialogue that we hope to fill with this review.

The broad aim of our review was to characterize the topical and methodological aspects of research on services for supporting success in work, education, and social participation among adults with an ASD and to propose recommendations for moving this area of research forward. First, we characterized the topical distribution of research to chart the terrain of inquiry and identify topics that are relatively neglected. Second, we summarized and critiqued methodological approaches that have been used to highlight issues of sampling bias and external validity. We also paid special attention to how the heterogeneity among people on the autism spectrum was represented in the literature. We conclude by discussing several issues and conceptual frameworks that will help inform future research. We did not aim to summarize specific study findings or rate the strength of evidence for particular interventions.

## Literature Review Methods

We sought reports of original research about services and interventions aimed at supporting success in work, education, independence, and social participation among adults aged 18 and older with an ASD. We limited our search to studies conducted in Canada, the United Kingdom, Australia, and the United States published between January 1, 2000, and December 31, 2010. Our strategy entailed searches of online databases, forward citation searches of articles from during or before the review period, backwards citation searches of reference lists from found articles, and article nominations from experts.

A study from the defined period was included if it met the following criteria. First, it had to include adults with an ASD either as a primary focus or as a main comparison group. Second, the study had to have a primary aim of

## Abbreviations

ASD	autism spectrum disorder
ICF	International Classification of Functioning, Disability and Health
ID	intellectual disability
IQ	intelligence quotient
SEP	socioeconomic position

## Clinical Implications

- The demand for expertise in treating adults with autism will continue increasing over time.
- The dearth of evidence about services increases burden on clinical judgment.
- Families may need extra psychosocial and financial support as they struggle to find services for adults with autism.

## Limitations

- Evidence about services for people with similar developmental or psychiatric conditions was not examined.
- The review focused on research from English-speaking countries.
- The review may have missed some studies.

describing or evaluating interventions, services, or supports explicitly intended to aid in the areas of independent functioning, school, work, or social participation. Third, the study had to be primarily focused on people with an ASD rather than on professionals or family members. We did not include articles that were primarily focused on describing the course and outcome of ASD in adulthood, comorbid conditions, neurological or physiological characteristics, genetic or biological aspects of ASD, diagnostic issues, caregiver well-being, organizational functioning, or articles about behavioural interventions that were not clearly linked to a functional social role or context. We did not include articles describing general outcomes among adults with an ASD, which sometimes briefly mention rates of service use. The accompanying In Review article by Dr Patricia Howlin and Dr Philippa Moss<sup>8</sup> reviews evidence about the course of ASDs and outcomes in adulthood.

## Literature Review Findings

Twenty-three studies met our inclusion criteria.<sup>9-31</sup> To contextualize how many studies we found, we estimated the total number of studies published on ASDs during the same period by experimenting with different search parameters using the online PubMed database on May 5, 2011, for reports written in English. The various search strategies all consistently identified about 11 000 studies.

Among the 23 studies reviewed, 21 were conducted in the United States and 2 in the United Kingdom. Nearly one-half of the studies came from 3 research groups: 5 from 1 group,<sup>9-13</sup> 3 from a second group,<sup>14-16</sup> and 2 from a third group.<sup>17,24</sup> Nine studies were in ASD journals, 6 in psychology journals, 3 in disability journals, and 5 in education or vocational rehabilitation journals.

## Distribution of Topics and Aims

Most studies were about employment ( $n = 16$ ) (Table 1). Fewer studies were about supporting success in postsecondary education ( $n = 1$ ), or independent living or social participation ( $n = 2$ ). Four studies cut across multiple topics.

**Table 1 Summary of the characteristics in reviewed studies, with data specific to subjects with autism aged 18 years or older**

Study	Sampling procedures	ASD diagnostic groups	n <sup>a</sup>	Age, years (mean)	Male %	Verbal <sup>b</sup> %	White %	SEP <sup>c</sup>
Employment								
Lattimore et al <sup>9</sup>	Sample	Autism	3	25–29	100	0	NR	NR
Lattimore et al <sup>10</sup>	Sample	Autism	5	26–38 (30)	100	0	NR	NR
Lattimore et al <sup>11</sup>	Sample	Autism	4	29–30	100	0	NR	NR
Lattimore and Parsons <sup>12</sup>	Sample	Autism	3	30–41	100	0	NR	NR
Lattimore <sup>13</sup>	Sample	Autism	4	31–44	100	0	NR	NR
Allen et al <sup>14</sup>	NR	PDD-NOS	2	19–22	100	NR	NR	NR
Allen et al <sup>15</sup>	NR	Autism, PDD-NOS, Asperger syndrome	2	18–25	100	NR	NR	NR
Burke et al <sup>16</sup>	NR	Asperger syndrome, PDD-NOS, autism	6	18–27	100	NR	NR	NR
Hillier et al <sup>17,a</sup>	Recruited through a university ASD clinic and local high school transition services offices	ASDs	9	18–36	89	NR	NR	Yes
Howlin et al <sup>18</sup>	Subset of participants in a UK-supported employment program	Autism, Asperger syndrome	117	18–56 (31)	81	NR	NR	Yes
Cimera and Cowan <sup>19</sup>	Case criteria applied to the Rehabilitation Services Administration 911 (Vocational Rehabilitation) database	Administrative designation of autism	11 569	(29)	80	NR	83	NR
Hurlbutt <sup>20</sup>	Subjects from a previous study, recruitment through a chat group and snowball sampling	Asperger syndrome, high-functioning autism	6	25–65	50	NR	NR	Yes
McDonough and Revel <sup>21</sup>	NR	Autism	2	22–27	100	NR	NR	Yes
Müller et al <sup>22</sup>	Telephone recruiting, invitation, and snowball sampling	Asperger syndrome, high-functioning autism, PDD-NOS, other ASD	18	18–62	72	NR	NR	Yes
Service needs assessment								
Bennett et al <sup>23</sup>	Clients of the UK Learning Disability Service who completed a previous questionnaire	Autism	9	(41)	89	NR	NR	NR
Social participation, employment								
Hillier et al <sup>24, b</sup>	Completers of a fee-based social–vocational support program	Autism, PDD-NOS, Asperger syndrome	13	18–23 (19)	85	NR	NR	NR
Employment outcomes								
Lawer et al <sup>25</sup>	Case criteria applied to US Vocational Rehabilitation System database	Administrative designation of autism	1707	18–65	84	NR	84	NR
Schaller and Yang <sup>26</sup>	Case criteria applied to the Rehabilitation Services Administration 911 (Vocational Rehabilitation) database	Administrative designation of autism	815	15–64	86	NR	78	Yes
MacLeod <sup>27</sup>	Case studies selected to represent diverse needs	Post-secondary education	2	NR	100	NR	NR	Yes
		Asperger syndrome						

Study of comprehensive service model

Author	Study Description	Age Range	Sample Size	Cost	Enrolment Rate	Service Cost
McClannahan et al. <sup>28</sup>	Participants in an Adult Life-Skills Program	Autism	15	21–35	87	NR
Sperry and Mesibov <sup>29</sup>	Recruitment via letters of invitation to support group members	Social skills ASD	18	22–49 (34)	94	100
Turner-Brown et al. <sup>30</sup>	Sample of participants in North Carolina's Division TEACCH program	High-functioning autism	11	25–55	91	NR
Van Bourgondien et al. <sup>31</sup>	Part random, part clinical-administrative assignment of program applicants	Residential program Autism	32	18–48 (25)	81	NR

<sup>a</sup> Some studies included participants outside the age range of our review and (or) from other disability groups. This column reports the number of study participants meeting our review's inclusion criteria of being aged 18 years or older and having an ASD.

<sup>b</sup> The percent of subjects who communicated verbally.

<sup>c</sup> Whether the study reported some aspect of SEP (income, wealth, educational attainment, or occupation) to characterize the sample characteristics. This criterion was not met if a study merely reported that participants had a job as a result of an intervention.

NR = not reported; PDD-NOS = pervasive developmental disorder not otherwise specified; Sample = sample from supported employment work site

Thirteen studies assessed the implementation or impact of an intervention or program.<sup>2,9–16,18,24,30,31</sup> The other 10 studies had a wide range of aims, including needs assessment and descriptive estimates of service enrolment rates. Only 4 studies included some estimation of service costs.<sup>18,19,25,26</sup>

Eight studies evaluated behavioural interventions aimed at either identifying task preferences or teaching specific job-related behaviours.<sup>9–16</sup> For instance, 3 studies assessed job skills training that taught participants to perform in a mascot costume in a retail setting.<sup>14–16</sup> Behavioural interventions were generally found to be efficacious.

Three studies aimed to understand what types of services are needed to support employment success.<sup>20,21,23</sup> Two of these 3 used qualitative methods that included asking people with an ASD about their experiences.<sup>20,21</sup> Sample sizes for these studies were small, ranging from 6 to 18. Some common themes emerged, including a need for ASD-specific supports and staff training, targeted help for difficulties with social communication and repetitive behaviours, and the need to attempt to match jobs to areas of individual strength while avoiding a model of intervention framed mainly around ameliorating client deficits.

Five studies evaluated group- and agency-level programs (as opposed to individual behavioural treatments) aimed at supporting vocational success,<sup>17,18,24</sup> social participation,<sup>30</sup> or residential success.<sup>31</sup> Results were generally positive and suggest it is feasible to impact measures of job placement, job retention, and satisfaction among clients and employers, as well as social participation and residential experiences.

Three studies featured analyses of data from the US Rehabilitation Services Administration system, though the years covered and sample sizes varied across studies.<sup>19,25,26</sup> Research questions included examination of changing enrolment trends, unit cost of service provision, and rates of job placement outcomes. One study highlighted the limitations for drawing conclusions from these databases, given the small amount of information available on diagnoses, impairment severity, and comorbidities.<sup>19</sup>

**Sampling and Study Design**

Studies varied widely in research design and in how thoroughly they reported sample characteristics. The sample sizes for the 3 US vocational services administrative database studies ranged from 815 to 11 569 (mean 4697). The remaining twenty studies had sample sizes ranging from 2 to 117 (mean 14). Most of these were convenience samples. Several studies did not report their sampling or recruitment procedures.

Sex was the only participant characteristic that was reported across all studies. The mean proportion of sample members who were male was 83% across the 3 large administrative data studies and 91% for the other studies.

All studies except one included information on age of subjects. The range of ages across studies was wide (18 to 65 years). However, studies tended to focus on younger

participants. Twelve of the studies were conducted using participants with a mean age of 30 years or younger.

Among the 13 studies that assessed an intervention, 6 used a single-subject design, 2 were experiments, and 5 were nonexperimental or qualitative.

Among the twenty studies not based on administrative enrolment data, 10 did not report how the participants' diagnostic classification was determined or verified. Eight of the twenty studies reported that diagnosis was made at some point by a qualified professional. Four studies verified the diagnosis using standardized measures, including the Childhood Autism Rating Scale, the Gilliam Asperger's Disorder Scale, the Autism Diagnostic Interview—Revised, and the Autism Diagnostic Observation Scale. Eight studies reported including participants with Asperger syndrome.

The heterogeneity of impairments among those with an ASD was inconsistently characterized. Seventeen studies included some measure of intellectual or functional abilities, with 9 reporting standardized test scores (often IQ or adaptive behaviours) and others using unanchored categorical descriptors (for example, severe-profound), with no definition of, or reference to, the criteria used for sorting participants into categories. Six studies characterized the verbal status of participants in some manner.

Comorbid health and mental health conditions are common among people with an ASD.<sup>32</sup> However, the assessment and reporting of comorbid conditions among reviewed studies was inconsistent and sometimes missing. Twelve studies reported on the presence of comorbidities.

### ***Reporting on SEP, Race, and Ethnicity***

SEP is a construct that describes the social and economic location of individuals and groups in a society's social hierarchy based on their income, wealth, education, and occupation.<sup>33–35</sup> None of the studies we reviewed characterized the income distribution of participants or their families. Eight studies included some information about the educational attainment of participants (typically whether they had graduated from high school). Three described the occupation of participants.

Eight studies included descriptions of the racial or ethnic distribution of participants. Only one study noted the possibility of sampling bias in comparison to the ethnoracial composition for the surrounding region.<sup>31</sup>

## **Discussion and Considerations for Future Research**

Taken together, these findings suggest the evidence base about services for adults with an ASD is underdeveloped and can be considered a field of inquiry that is relatively unformed. Extant research does not reflect the demographic or impairment heterogeneity of the population, the range of services that adults with autism require to function with purposeful lives in the community, or the need for coordination across services.

We found a lack of attention to SEP in ASD research. This was surprising because impoverishment is common in the general population and is associated with decreased access to services and adverse developmental outcomes in non-ASD populations. For instance, as of 2009, 1 in 5 US children aged 17 years or younger were living below the federal poverty line. Given an ASD prevalence rate of 1 per 110, this translates into about 163 000 children aged 17 years or younger with an ASD in the United States who were living in poverty. As these children age toward adulthood, it will be important to determine how poverty influences developmental trajectories in those with an ASD, the related impact on need for supportive services as adults, and access to services in adulthood.

Research on poverty and ID has documented 2 distinct processes that can increase the risk that adults with an ID will have low SEP.<sup>33</sup> First, the process of raising a child with an ID takes a cumulative toll on a family's financial well-being, both directly (for example, through out-of-pocket expenditures for interventions) and indirectly (for instance, if one parent forgoes wage earning to stay home to care for the child). Second, having an ID is associated with an increased risk, relative to those without an ID, for unemployment as an adult and a subsequent lowering of earning power. These processes are not mutually exclusive, and suggest similar lines of inquiry for research related to ASDs.

Including measures of SEP in future ASD services research can open a door to 3 general types of research question.<sup>34</sup> First, stratification of estimates of access to services by SEP measures will enable the description and monitoring of inequities in service use across strata. Second, SEP measures can be used for statistical adjustment to obtain conditional estimates of the association between non-SEP factors (for example, impairment severity) and measures of service access and related outcomes. Third, including SEP measures in research can enable the examination of underlying mechanisms that may give rise to unequal access and outcomes.

We also found a relative neglect of issues related to ethnoracial diversity. This stands in contrast to Canada and the United States becoming increasingly more demographically diverse. Further, the past decade has seen a steadily expanding body of evidence about racial disparities in health outcomes and access to health services across a wide range of health conditions and service systems. The connections among race, service access, and health outcomes are complex, historically contingent, and vary across countries.<sup>36</sup> Nonetheless, some useful general frameworks for inquiry have emerged.

A landmark report in the United States posited that racial health disparities need to be examined at 2 main levels: the systemic level of organizations, laws, and policies; and the individual level of patients and providers.<sup>37</sup> The report emphasized the importance of gathering and disseminating basic descriptive information about the extent of disparities



as a tool for justifying and motivating change at all levels. This would be an important starting point for ASD services research, which has often neglected racial differences.

Attention to issues of service costs and efficiency is also lacking. The recent global economic recession has increased pressure on publicly funded systems of care to do more with less.<sup>38</sup> Social welfare mechanisms for the support of aging citizens are becoming more financially strained as the ratio of current workers to retirees shrinks. Thus the growing number of adults with autism is occurring in a broader and adverse sociopolitical context of declining financial resources that are available for the support of aging citizens. To increase relevance to policy-making, future research must examine the cost and efficiency of service provision because these factors tend to be highly influential with policy-makers.<sup>39</sup>

The heterogeneity of both abilities and challenges exhibited by people on the autism spectrum is vast. Severity of impairment and the presence of comorbid conditions have significant implications for service needs.<sup>40</sup> However, few of the reviewed studies examined the implications of this heterogeneity for service provision, nor did most studies adequately characterize the heterogeneity of their participants. Moving services research forward will entail characterizing the wide diversity of service needs in this heterogeneous population and careful thinking of ways to target services accordingly.

Most of the reviewed studies focused on adults aged 29 years or younger. Future research on services for adults with an ASD needs to more consistently reach into middle and older adulthood, as the needs and intervention models for these groups are likely to be different than for those who are in their 20s.

The reviewed research also failed to note that the nature and meaning of aging from adolescence to adulthood has undergone a significant historical shift in recent decades, resulting in a new stage of psychosocial development called emerging adulthood. In the early 1990s, Arnett<sup>41</sup> suggested that the transition from adolescence to adulthood is no longer best represented by a normative sequence of social role transitions, such as ending formal schooling, moving out of the parental home, getting married, or having children—which are now more often achieved in a gradual, disordered fashion.<sup>41–43</sup> Instead, he identified 3 criteria defining the transition to adulthood that could be measured in future services research: independence in decision making, being responsible for one's own person, and financial independence.<sup>44</sup>

Not a single reviewed study examined patterns of service use across multiple service providers or sectors. However, ASDs are pervasive (by definition) regarding how many areas of development and function are affected. People with an ASD often need various kinds of support from multiple service providers and across different sectors and systems of care.<sup>45</sup> Future ASD research needs to investigate the prevalence, management, and consequences

of simultaneous engagement in multiple types of services. A particular emphasis is needed on the issues of care coordination, the extent to which families and individuals need support navigating complex multi-sectoral systems of care, and research on the effectiveness of models for supporting care navigation.

Most of the reviewed studies focused on life functioning in the area of employment. Gerhardt<sup>6</sup> noted a similar predominant focus on employment topics related to transition planning. However, work is but one dimension of adult life. Future research needs to examine services aimed at supporting positive functioning in a wider array of adult social roles and settings.

Few reviewed studies were explicitly anchored in a conceptual model of disability or human development. Several ideas from the broader field of disability research could be useful for this area of research. The capability approach is rooted in the seminal work of Nobel economist Amartya Sen and has been adapted by others to address disability-related issues.<sup>46–53</sup> From this perspective, promoting positive human development means expanding choices for all people to achieve higher quality of life and well-being. Capability is based on a convergence of individual abilities, an enabling socioeconomic context that fosters multiple options, and the freedom to make choices for oneself. In turn, having capabilities can translate into achieved functioning through agency in areas such as health, mental health, social role attainment (having a job, going to school), and social participation. This framework suggests the broad aim of service provision is to improve capabilities so that people can attain more positive achievements in multiple domains of life functioning.

Capability approach's simultaneous focus on individual abilities and the social context imply that interventions, at either level, can have potential for positive impact on achievements. The related implication is that intervening only at the level of individual abilities cannot, by itself, lead to enduring positive achievements at the population level. Intervention must also occur at the level of the social environment to achieve enduring population-level change.

Another useful conceptual model of disability is the World Health Organization's ICF.<sup>54</sup> The model acknowledges the influence of personal and environmental contextual factors on how disability is experienced by an individual, and how the confluence of all these factors forms the disability experience. The ICF uses a biopsychosocial model of disability, combining elements of both biomedical and social perspectives of disability. An advantage of the ICF is that it provides a detailed system of classification for activity participation and limitation indicators that could be used by programs for the sake of individual assessment and intervention goal setting, as well as for program evaluation and performance measurement at the agency and community levels.

In addition to these conceptual models, future research on services for adults with an ASD should also draw from



the ideas and methodologies of the more fully formed field of health services research, which often organizes research questions into aims related to effectiveness, equity, efficiency, and access.<sup>55-57</sup> Effectiveness research aims to build an evidence base of what works in real-world settings. Equity research puts the focus on questions of disparate access and outcomes stratified by race, ethnicity, sex, and SEP. Efficiency research highlights issues of cost and finding ways to make the most of finite financial resources. Access to services can be usefully defined along 5 dimensions: availability (do services exist?), affordability (are they affordable?), accessibility (are they geographically and physically accessible?), acceptability (what are the attitudes of youths and families toward currently available options?), and accommodation (how are the currently available options organized?). Future research on services for adults with an ASD needs to address this broad set of potential aims.

## Conclusion

The evidence base on services for adults with an ASD is inadequate for informing policy and program decisions to meet the needs of this growing population. Nonetheless, advocacy groups, service providers, and policy-makers are forging ahead to develop and offer needed supports and programs. This creates an opportunity to generate practice-based evidence in partnership with innovative providers on the front lines of service delivery. A recent US report suggested researchers should collaborate with program innovators using community-based participatory research methods to develop relevant research aims and to shorten the time lag between discovery and translation.<sup>7</sup>

Several common themes were present in the conceptual frameworks. At the individual level, these include calls for a stronger emphasis on measuring self-determination, quality of life, and participation in decision making. Because disablement is seen as the product of the interaction between individual abilities and the surrounding social context, intervention and measurement must occur at organizational, community, and societal levels to achieve enduring improvements at the population level.

Future studies must examine issues related to cost and efficiency, given the broader sociopolitical and economic context of service provision. There is a need for research on how SEP, demographic diversity, and impairment heterogeneity have implications for building an evidence base that will have greater external validity. Last, the scope of autism services research needs to broaden to include the full array of services for adults across domains, including housing, health care, criminal justice, and financial planning.

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