RESEARCH ARTICLE

Predictors of Changes in Daily Activity in Transition-Age Autistic Youth

Jonathan A. Weiss, Jonathan K. Y. Lai, Vivian Lee, and Yona Lunsky

Transitioning into adulthood is fraught with challenges for autistic youth. A greater understanding of the facilitators of community involvement in school and employment during this period is warranted. The current study examines changes in service need and receipt, and the stability of accessing daily structured activities, for autistic young adults over their transition period compared to adolescents and adults that did not enter the transition period. Baseline caregiver survey data were taken from the Canadian Autism Spectrum Disorders Alliance National Autism Needs Assessment Survey in 2014, and caregivers (n = 304) completed the same set of questions in 2017 about sociodemographic factors, clinical need, service receipt and typical weekday activities. Three cohorts were compared: (1) pretransition age youth, (2) transition-age youth, and (3) young adults who were past transition age. Results suggest that transition-age youth were found to have a unique set of priority service needs compared to pre transition-age adolescent and to adult groups, and both transition-age and adult groups had lower levels of priority service receipt compared to pretransition-age adolescents. The transition-age group experienced the greatest loss of structured weekday activity between time points, and were more likely than pretransition-age adolescents to not have structured weekday activities at Time 2. A recovery of structured daily activity was not observed in young adults. Our results highlight the tumultuous nature of the transition period for autistic youth, which continues into adulthood, and the urgent need for supports during this time. ***Autism Res** 2021, 14: 324–332*. © 2020 The Authors. *Autism Research* published by International Society for Autism Research and Wiley Periodicals LLC.

Lay Summary: This research highlights that autistic young people who are transitioning to adulthood are at greatest risk of losing structured weekday activities, and that once in adulthood, many continue to struggle to obtain meaningful community engagement. These results can help guide the design of adolescent and young adult transition programs.

Keywords: autism; transition-age youth; services; community; schooling; employment; adulthood

Introduction

Emerging adulthood is a life stage that is full of challenges and concern for autistic young adults and their families. Emerging adulthood is defined by experiences of transitions in social, economic, and adaptive roles, which take place throughout a person's later teenage and young adult years (i.e., 14–25 years of age) [Arnett, 2000, Sawyer, Azzopardi, Wickremarathne, & Patton, 2018]. This is also a period in which individuals leave secondary school and are expected to shift into adult health and community service delivery from child services [Cooley & Sagerman, 2011]. For many on the spectrum, achieving traditional milestones of completing formal postsecondary education, establishing financial independence, attaining a self-identity, and finding a vocation can be particularly difficult [Wehman et al., 2014].

Autistic adolescents are at risk of losing services as they transition to adulthood. This "service cliff" has been identified in education, health, and social service sectors [Roux, Shattuck, Rast, Rava, & Anderson, 2015]. For instance, in a cross-sectional study, up to 40% of young autistic adults in the United States received no services post-high school [Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011], 50% were not enrolled in postsecondary education within 2 years post-high school, and 55% did not have a job within 6 years [Shattuck et al., 2012]. A more recent cross sectional study of children and adults showed that individuals past the high school-age in the United States received fewer services while reporting high unmet need in specific domains (speech/language therapy, one-to-one support, social skills training, medication management) compared to younger groups [Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016]. Using administrative health insurance data, Nathenson and Zablotsky [2017] found reductions in the use of health services for autistic young adults, including inpatient and outpatient

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hospital use, and healthcare home visits. In the same study, the proportion of youth who visited the Emergency Department (ED) was consistent, leaving the authors to suggest that ED use may be a substitute for the loss of other services. In addition, youth with concurrent intellectual disability (ID) used more medical services overall and had a steeper decline in their service use as they aged. Challenges with service use may also be predicated by the changing service needs that people have as they transition through emerging adulthood. In a cross-sectional study comparing age groups of autistic individuals in Canada, Lai and Weiss [2017] found that while there were no differences in the total number of services *received* between groups of individuals aged 12–17, 18–24, and 25+ years, there were differences in the types of priority *needs* reported by caregivers. Caregivers of 12–17-year olds identified behavior management (28.4%) and specialized summer camps (39.7%) as priority needs that were not present in the older groups. Caregivers of the "adult" groups (18–24 and 25+ years) equally identified housing, employment training, and adult programming, as unique priority needs. Research also highlights the emotional challenges and considerable financial burden placed on families to support the success of autistic individuals across the life course, and in particular when they transition into the adult system [Knapp, Romeo, & Beecham, 2009].

One of the biggest challenges in the transition-age period is that changes can result in a loss of engagement in structured weekday activities in the community. Meaningful community activity is often operationalized as either being engaged in education or some regular daily vocation, including either supported or independent employment or volunteerism. These programs are important because participation in purposeful and meaningful activities has been shown to increase life satisfaction [Wilcock, 2005], and health and well-being [Larson & Verma, 1999] in autistic young adults. Despite having expectations and goals for participating in some form of postsecondary educational or vocational activity [Sosnowy, Silverman, & Shattuck, 2018], autistic young adults often struggle to achieve these outcomes [see Friedman, Warfield, & Parish, 2013; Henninger & Taylor, 2013; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Shattuck et al., 2012]. In a longitudinal cohort study, Taylor and Seltzer [2011] found that following high school exit, significantly more autistic young adults with ID remained involved in a regular structured weekday activity, such as adult day services, compared to those without ID. Remarkably, 23.5% of young adults without ID failed to be engaged in any sort of structured weekday activity. Further, over a 12-year period, fewer than 25% of adults were found to be consistently engaged in employment or education, and 33% were never engaged [Taylor, Henninger, & Mailick, 2015].

There is a pressing need to understand the dynamics of service receipt and community involvement through the -transition-age period. There is a lack of longitudinal research that examines changes that occur across the transition periods, and most studies use the exit from high school as the indicator of transition [e.g., Taylor & Seltzer, 2011]. While this adds to the internal validity of the study by having a clear event, in reality, emerging adults can experience many changes in health, education, and social services at different points in time [Sawyer et al., 2018], and selecting any one event as the indicator may fail to capture the entire transition period, omitting other crucial changes that occur in that timespan. In conceptualizations of emerging adulthood, using key discrete events in a person's life, such as exit from high school, is particularly useful for assessing successful (or unsuccessful) transitions from that particular event, while examining broader periods of experience reflects that the process of transition is gradual, with different entry points for each person [Arnett, 2000]. A "phased" approach to studying transition periods from pretransition-age autistic youth who are emerging into early adulthood can help to capture the cascading changes and overlap in individual services over time.

In the current study, we used a 3-year period to examine the changes that autistic youth and young adults experience in service receipt and in participation in structured weekday activities, over their transition period. We operationalized the transition phase as anyone who was under 18 years of age at the baseline period but who crossed this age during the 3 years of the study, thus ending up between 18 and 20.9 years of age at Time 2 (transition-age group). We compared the transition-age group to two other groups: to adolescents who have yet to enter into this period (i.e., older adolescents who within the 3-year period of the study remained under 18 years of age, ending up 15–17.9 years of age at Time 2; adolescent group), and to emerging adults who had already passed the transition phase at Time 1 (ending up at 24–27 years of age at Time 2; adult group). Specifically, we

1. Compared the priority service needs of the transition-age group to the other age groups. We expected that the transition-age group would have a different pattern of service needs at Time 2 than the adolescent group, while being similar to the adult group that were not in the transition period (Hypothesis 1).
2. Compared the degree to which the three groups received services that were in line with these priority service needs. We expected that the transition-age group would be no different than the adult group at Time 2 and would have less priority receipt after going through the transition period (Hypothesis 2).
3. Compared the rates of participation in structured activities, whether it be employment, education, or other structured daily activities, between the three groups. We expected that the transition-age group would be least likely to participate in structured activities at Time 2 (Hypothesis 3), and be most likely to lose the structured activities that they had at Time 1 and not gain another kind of activity (Hypothesis 4).

Methods

Survey

The baseline data for this study were taken from the caregiver report version of the Canadian Autism Spectrum Disorders Alliance (CASDA) National Autism Needs Assessment Survey [for more information, see Weiss, Whelan, & McMorris, 2014]. CASDA is a national not-for-profit organization that collaborates with key Canadian stakeholders to guide the development of the country's National Autism Strategy to address critical gaps in funding and support for autistic individuals and families. The online survey was sent out using the Qualtrics survey platform as a means to collect information about the ongoing perceived needs and service gaps as identified by family caregivers. The survey consisted of standard demographics questions, questions regarding the family caregiver and child's health, financial status, services need and use within last 6 months. Baseline survey recruitment occurred from April to July 2014 [see Lai & Weiss, 2017 for details]. Caregivers who elected to be contacted for further research were contacted again between February and March 2017, and the same series of questions were asked. Informed consent was obtained at the beginning of the survey. This research was approved by York University's Ethics Review Board.

Participants

In total, 1632 caregiver respondents (97.9% parents, 2.1% grandparent) with an autistic individual within their care and in the target age (14–29 years) agreed to be contacted for the follow-up survey, and 330 completed the survey at Time 2. Of these, 304 had a score of at least 12 on the Social Communication Questionnaire (Lifetime Version) [Rutter, Bailey, & Lord, 2003], which is a cutoff often used in online research to support parent reported autism diagnosis [Chandler et al., 2007; Corsello, Hus, & Pickles, 2007; Daniels et al., 2012; MacMullin, Lunsky, & Weiss, 2016; Zablotsky, Bradshaw, & Anderson, 2012], and the rest ($n = 26$) were excluded from analysis. Of these, there were 209 pretransition-age youth (adolescent group; currently 14–17 years old; M age = 14.5, SD = 1.8; 83.3% male), 43 were transition-age (transition-age group; who became older than 18 years during the 3 years; M age = 19.4, SD = 0.5; 93% male), and 52 young adults (adult group; currently 25–29 years old; M age = 26.5, SD = 1.4; 78% male). The majority of adolescents were living with their family member (98.6%) compared to 86% of those in the transition-age period, and to 69% of adults.

Measures

The measures used in this longitudinal study to describe the autistic individual are described in detail in Lai and Weiss [2017]. While not the same as independently verified ascertainment, caregiver report of clinician provided diagnosis has been shown to be valid [Daniels et al., 2012] and this, along with other variables, has been used by multiple large studies [Kogan et al., 2008, 2009; Lin, Stella, & Harwood, 2012; Shattuck et al., 2012; Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011]. Selected variables are briefly described below.

Sociodemographic factors. Descriptive sociodemographic measures included age, gender (male vs. nonmale), residency (living with family vs. other living arrangements). We also asked whether respondents could afford the services they needed for the autistic person (yes/no).

Priority service receipt. Caregivers reported on the services that were received in the last 6 months, using a checklist of 23 services and an "other" option that was recoded as needed [see Lai & Weiss, 2017 for details]. Using this list of services, we asked caregivers to choose the top five current priority service needs for the autistic person (priority needs). We then calculated a priority receipt score (0–5) based on the number of priority service needs identified by an individual that were being addressed by their service receipts. No caregivers selected fewer than five services. The forced cap at five services was originally developed in the baseline survey to report on the most pressing service needs of the autism community, as opposed to reflecting all possible needs. This was done to better understand the kinds of service gaps that exist in the context of limited resources and options, reflecting the experience of CASDA stakeholders.

Typical structured weekday activity. We asked caregivers what their son or daughter (child) did during a typical weekday over the last 4 months. Caregivers selected from the following list: in school, independent employment, supported employment, vocational day program (i.e., sheltered workshops), supported day program (e.g., recreational programs, but not vocational/ employment), more than one of the these activities, any other activities (e.g. volunteering), or no structured daytime activities. Responses were recoded into school, employment (both part time and full time), other activity (including volunteering, day programs, etc.) and no activity.

Clinical characteristics. A number of general clinical characteristics were also measured, to assess potential differences in the extent of clinical need between groups. *Overall health status* was measured by asking about current health on a 5-point Likert scale, dichotomized as 0—poor/fair health to 1—good/very good/excellent health. The *presence of ID* was based on caregiver report of any diagnosis of ID given by a health professional. Total number of *current physical health conditions* was summed from a list of 12 possible physical health conditions and an open-ended statement for any other condition, which was recoded. Total number of *current mental health conditions* were assessed through a list of current formal psychiatric diagnoses (anxiety disorder, attention deficit hyperactivity disorder/attention deficit disorder [ADHD/ADD], depression, obsessive–compulsive disorder, schizophrenia/psychotic disorder or other, where other was recoded). The number of behavioral concerns was the sum of current caregiver concerns related to aggression, self-injury, hurting other, destruction of property, and problems with the law. This list of concerns was selected in discussion with CASDA stakeholders during the development of the national autism survey and identified as the most common behavioral concerns by caregivers [see Lai & Weiss, 2017 for details].

Data Analysis

Analysis was done using IBM SPSS version 24. A series of bivariate chi-square analyses compared the rates of endorsed priority service needs between the transition-age group to the adolescent and adult groups (Hypothesis 1). To control the family-wise error rate and multiple comparisons for Hypothesis 1, the Holm–Bonferroni adjustment (Holm adjustment) was used for each hypothesis test. While not as conservative as the classic Bonferroni adjustment, the Holm mechanism allows for a ranked adjustment based on the order in which differences were found, considered to be a more balanced approach to managing Type I and Type II error with relatively small samples [Abdi, 2010]. To be deemed statistically significant, the reported P value must be lower than the Holm-adjusted P value. A two-way repeated measures ANOVA (with time as the within-subject factor and age group as a three-way between-subject factor) tested the hypothesis that the transition-age group would have the lowest degree of priority service receipt at both time points (Hypothesis 2). The interaction between group and time was also examined.

To test the hypothesis that the three groups would differ in their rates of structured daily activities (Hypothesis 3), chi-square statistics were calculated for Time 1 and Time 2 scores separately, comparing group percentages of those with some form of structured daily activity (collapsing endorsements of participation in school, employment, other activities) vs. none. We also examined the kinds of daily activities endorsed for each group.

To test the hypothesis that the transition-age group would be most likely to lose structured activities between Time 1 and Time 2 (Hypothesis 4), cases were grouped based on having a structured daily activity at each time point. Those that had an activity at Time 1 and had no activity at Time 2 were categorized as those that "lost activity." Those that had no activity at Time 1 and had one at Time 2 were categorized as those that "gained activity." Those with an activity at both timepoints were those that "always had an activity" while those that did not have an activity at either timepoint were categorized as those that "never had an activity." Chi-square analyses compared the proportion that gained or lost activity between the transition-age group and the adolescent and adult groups. Fisher's exact test was used when $n < 5$ in any cell.

Results

Preliminary group comparisons in clinical characteristics indicated similar clinical profiles. As shown in Table 1, there were no group differences in the rate of ID, at approximately 44.1% for the entire sample. The percentage of individuals with either a parent report of overall poor or fair health status (vs. good to excellent) increased from the adolescent group to older groups. There were no differences between groups in rates coming from rural/remote (20%), suburban (39%), and urban (41%) communities (χ^2 [4, 304] = 1.78, $P = 0.78$), in reporting having financial trouble (20%, χ^2 [2, 304] = 0.31, $P = 0.86$), or in being able to afford services that they need (69%, χ^2 [2, 304] = 0.31, $P = 0.86$). Total rates of behavioral concerns, mental health conditions, and physical health conditions did not differ between groups. There were no differences in demographic, clinical, or service variables at baseline between responders and non-responders to the follow up survey (all $P > 0.10$, see Table S1 for specific characteristics at baseline).

Priority Service Needs

As shown in Table 2, with the Holm adjustment, there were three instances where the transition-age group had a statistically different proportion of priority needs compared to adults. Caregivers of the transition-age group reported a higher percentage of selected priority needs for life skills training (72.1% vs. 38.5%) and a lower endorsement for diagnostic assessments (0.0% vs. 19.2%) compared to adults. There was also a difference in post-secondary education needs (51.2% vs. 25%; $P = 0.009$) though not at the level of the Holm adjustment (0.004). Caregivers of the transition-age group were more likely than caregivers of adolescents to list priority needs related to housing (51.2% vs. 7.7%), postsecondary education (51.2% vs. 23%), and employment or adult day programs (74.4% vs. 16.7%). The caregivers of the transition-age group were less likely to identify specialized summer camps as a priority service need (11.6%) compared to caregivers of adolescents (34.9%).

Table 1. Sample Demographic and Clinical Characteristics

	% or Mean (SD)					
	Adolescent group (n = 209)	Transition-age group (n = 43)	Adult group (n = 52)	Overall (n = 304)	χ^2 or F	P value
Mean age (years)	14.47 (1.8)^{a}	19.42 (0.5)^{b}	26.5 (1.4)^{c}	17.23	1259.43	<0.001
Male	83.3%	93%	78%	83.6%	4.48	0.10
Living with family	98.6%^{a}	86%^{a}	69.2%^{b}	91.8%	49.65	<0.001
Health status (poor/fair)	4.3%^{a}	14.0%^{b}	17.3%^{b}	7.9%	12.21	0.002
Physical health conditions	1.39 (1.31)	1.61 (1.43)	1.73 (1.34)	1.48 (1.33)	1.56	0.21
Behavioral concerns	1.14 (1.36)	1.05 (1.33)	1.08 (1.33)	1.12 (1.34)	0.10	0.89
Mental health conditions	3.50 (1.07)	3.31 (0.89)	3.63 (0.97)	3.49 (1.03)	1.24	0.29
Intellectual disabilities	45.0%	37.2%	46.2%	44.1%	0.98	0.61

Note. Clinical characteristics were taken from data collected at Time 1. Values within the same row that differ are denoted by different superscripts a and b. The range for physical health conditions was from 0 to 11. The range for mental health conditions was from 0 to 4. The range for behavioral concerns was from 0 to 5.

Table 2. Priority Service Needs by Age Group

				Adolescent vs. transition-age		Transition-age vs. adult	
	Adolescent group (n = 209) (%)	Transition-age group (n = 43) (%)	Adult group (n = 52) (%)	χ^2 (P value)	Holm corrected P value	χ^2 (P value)	Holm corrected P value
Recreation	45.9	27.9	36.5	4.73 (0.03)	0.006	0.80 (0.37)	0.008
Social skills	63.6	48.8	44.2	3.29 (0.07)	0.007	0.20 (0.65)	0.01
Activity based	46.9	25.6	36.5	6.60 (0.01)	0.004	1.31 (0.25)	0.006
Specialized summer camps	34.9	11.6	13.5	9.06 (0.003)	0.004	0.07 (0.79)	0.03
Housing	7.7	51.2	38.5	52.72 (<0.001)	0.003	1.54 (0.22)	0.005
Diagnostic assessments	12.4	0	19.2	5.97 (0.02)	0.005	9.24 (0.002)	0.003
Respite	25.4	18.6	28.8	0.89 (0.35)	0.01	1.35 (0.25)	0.005
Transportation	1.4	7.0	5.8	4.71 (0.03)	0.006	0.58 (0.84)	0.01
Mental health	37.8	39.5	38.5	0.05 (0.83)	0.01	0.11 (0.91)	0.02
Behavioral management	29.2	16.3	9.6	3.02 (0.08)	0.008	0.95 (0.33)	0.007
Community safety	24.9	23.3	9.6	0.05 (0.82)	0.03	3.30 (0.07)	0.004
Crisis intervention	5.3	4.7	5.8	0.03 (0.87)	0.05	0.06 (0.81)	0.05
Life skills	52.2	72.1	38.5	5.73 (0.02)	0.005	10.71 (0.001)	0.003
Postsecondary education	23.0	51.2	25.0	14.13 (<0.001)	0.004	6.92 (0.009)	0.004
Employment or adult day programs	16.7	74.4	53.8	60.77 (<0.001)	0.003	4.28 (0.04)	0.004
Other	3.3	2.3	0	0.12 (0.72)	0.01	1.22 (0.45)	0.006

Note. Data shown are of priority service needs at Time 2. P values reflect Holm corrections.

Priority Service Receipt

The repeated measures ANOVA testing the rate of priority service receipt indicated a main effect for age group (F [2, 297] = 3.79, P = 0.02), but not for time (F [1, 297] = 1.35, P = 0.25). There was also no interaction between time and group (F [2, 297] = 0.30, P = 0.74). The caregivers of the transition-age group reported a lower rate of priority services to meet their priority needs when compared to the caregivers' of the adolescent group. Post hoc analyses indicated that at Time 1 and Time 2, the same pattern of results emerged, with a lower priority receipt scores in the transition group (Time 1: M = 0.98, SE = 0.21; Time 2: M = 0.95; SE = 0.19) compared to the adolescent group (Time 1: M = 1.48, SE = 0.10; Time 2: M = 1.38, SE = 0.09; Time 1: P = 0.03; Time 2: P = 0.04), but no difference compared to the adult group (Time 1: M = 1.33, SE = 0.19; Time 2: M = 1.08, SE = 0.17; both P > 0.05).

Structured Weekday Activity

As shown in Figure 1, a different pattern of daily activities was apparent across the three groups. The three groups differed in the rates of having no structured daily activities at Time 1 (χ^2 [2, 304] = 66.16, P < 0.001) and Time 2 (χ^2 [2, 302] = 43.91, P < 0.001). At Time 1, the transition-age group was not more likely to lack daily activities (4.7%) compared to the adolescent group (1.4%; Fisher's

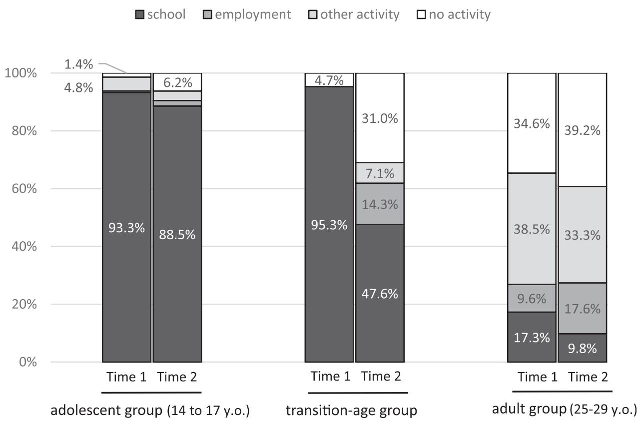

Figure 1. Distribution of structured community activity at Time 1 and Time 2 by age cohort.

exact test = 0.20) but was more likely compared to the adult group (33%; χ^2 [1, 103] = 11.07, $P = 0.001$). At Time 2, the transition-age group was more likely to have no activity (31.0%) compared to the adolescent group (6.2%; χ^2 [1, 251 = 23.04, $P < 0.001$), but were similar to the adult group (39%; χ^2 [1, 93] = 0.69, $P = 0.41$).

In terms of those that were engaged in some form of structured daily activity, while high rates of school engagement were noted for the transition-age group at Time 1 (95.3%) when they were all under 18 years of age, this decreased to 47.6% at Time 2 when they ended up in the transition period. Only 17% of adults were in some form of school at Time 1, decreasing to 9.8% at Time 2. As could be expected, some of the reduction of school engagement in the transition-age group was met with an increase in employment (14%) and day programs (7%) at Time 2. At Time 1, only 9.6% of the adult group was reported to be in an employment setting (increasing to 17.6% at Time 2), and another 38.5% was attending some other form of daily activity (e.g., nonemployment day programs; decreasing to 33.3% at Time 2). Across the entire sample, a Mann–Whitney *U* calculation indicated that a higher number of priority receipts at Time 2 was associated with have at least some form of structured activity ($Z = 2.95$, $P = 0.003$).

The pattern of maintaining, losing or gaining activity over the 3-year period was different across the three age groups (χ^2 [6, 302] = 88.54, $P < 0.001$). As shown in Figure 2, the transition-age group was more likely to lose access to structured weekday activity (28.6%) compared to the adolescent group (5.7%; χ^2 [1, 251] = 21.08, $P < 0.001$) and a trend emerged when compared to the adult group (13.7%; χ^2 [1, 93] = 3.13, $P = 0.07$). The adolescent group had a greater percentage of accessing structured weekday activities at both time points (92.8%) compared to the transition-age group (66.7%; χ^2 [1, 251] = 23.42, $P < 0.001$) and adult group (52.9%; χ^2 [1, 260] = 51.15, $P < 0.001$). The adult group was more likely to not have any structured activity at both time points (25.5%) (Figure 2).

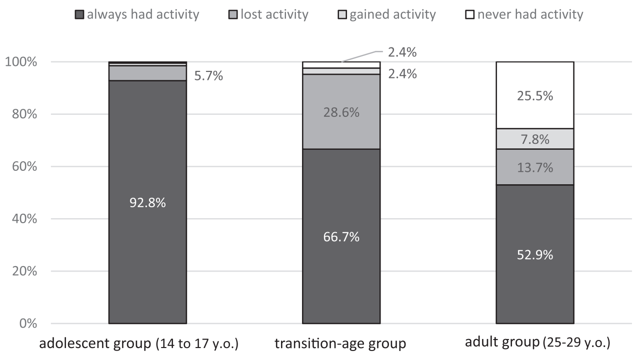

Figure 2. Change in structured community activity by age over 3 years.

Discussion

Despite significant investments in Canada for autistic youth, this study showed that the potential for a transition related loss in support and activity still exists. Our study confirms that the transition period is marked by changes in priority service needs and structured daily activity. We have long known about the loss of services and of activities that can occur during transitions, but few of these studies follow adolescents and young adults over time or consider transitions beyond a specific event (such as leaving high school). No studies have looked at this "service cliff" prospectively in Canada, where healthcare is publicly funded, educational services are likewise funded until age 21, and where social services are intended to support autistic youth as they transition into adulthood.

Many of the results pertaining to the caregiver reports of the transition-age group appear to reflect the evolving aspirations of transition-age youth for growth into adulthood and independence. For instance, caregivers in this age group were more likely to report needing postsecondary supports compared to both caregivers of adolescents and of young adults, as well as more need for life skills training compared to caregivers of adults, and housing and employment supports compared to caregivers of adolescents. In Canada, it is likely that almost all of the transition-age individuals would have been engaged in school or some form of structured education program prior to entering into the 18–21-year age range, given mandated educational requirements, and this higher need for postsecondary supports reflects a logical next step in searching for the next educational opportunity. The heightened need for postsecondary and employment services by the transition-age group speaks to their needs for what in some jurisdictions is called "vocational rehabilitation"; funding initiatives that are meant to provide employment or educational services to people with disabilities [Rast, Roux, & Shattuck, 2019]. Rast et al. [2019] note that, in the United States, while up to 60% of transition-age autistic people end up being employed following vocational rehabilitation, only approximately 18% of eligible individuals received postsecondary education through such services, significantly fewer than similarly aged individuals with other disabilities.

Similarly, across jurisdictions, supportive housing has been described as inadequate in terms of the capacity to meet the kinds of needs that exist, and in terms of the flexibility of choices to suit people's preferences [Prince, Kameka, & Prince, 2016, pp. 297–311]. In our study, approximately half of the transition-age group and one third of the adult group had housing as a priority need. If we are to support transitions to adulthood, policies are needed that realize a person's rights to access meaningful residential and vocational outcomes, with the capacity to deliver on the scope of the need.

The transition-age group received fewer services to meet their priority needs compared to the adolescent group, which may reflect this "service cliff" [Roux et al., 2015]. Other research has found that even autistic adolescents can experience a reduction in service receipt, particularly those without ID, which continues or can become even greater post high school [Laxman, Taylor, DaWalt, Greenberg, & Mailick, 2019]. Transition planning is an integral component to addressing these service disparities, and research highlights the importance of planning before actual transition as an important component for continuity of access [Cheak-Zamora, Yang, Farmer, & Clark, 2013; Hendricks & Wehman, 2009]. In their recent qualitative study of barriers and needs around transition planning, Kuo, Crapnell, Lau, Anderson, and Shattuck [2018] found that the "earlier the better" theme was central across interviews, with transition planning and preparation ideally being "a dynamic process" that is lifelong in nature, rather than one that begins when one becomes or is close to becoming an adult. These authors further emphasized how promoting functional skill development and independence should be an ongoing aspect of education, with a concerted effort focused on building the systemic capacity for success that can accommodate unique needs, abilities, and interests. In future studies it will be important to assess whether individuals who access their priority receipt also received earlier or more intensive transition planning and support.

Our longitudinal analysis indicates a remarkable shift in structured weekday activity for the transition-age group. Transition-age individuals were most likely to lose structured activities and not gain any other activity at Time 2. Notably, engagement in school decreased from 95% to 48%, while there was an increase in employment, to 14%, and other day programs, to 7%. At the same time, this left 31% of transition-age individuals without any structured daily activity at Time 2, at similar rates to young adults who were not in the transition period. This pattern suggests that many young adults find themselves without regular activities posttransition, and that this loss likely begins to occur between 18 and 21 years of age. This loss of activity is highly problematic and is associated with broader psychosocial risks; there is some research showing that transition-age autistic individuals who experience "vocational/educational disruption" have lower quality of life and more mental health problems than individuals who do not experience this disruption post-high school, and that these issues may even precede the disruption or be linked in bidirectional ways [Taylor & DaWalt, 2017].

It is critical that autistic young adults have access to proactive evidence-based effective approaches to improve the likelihood of meaningful community engagement. For example, White et al. [2019] developed and evaluated the efficacy of the Stepped Transition in Education Program for Students with ASD to improve self-determination and self-regulation for psychosocial readiness for graduating from secondary school and for the demands of early adulthood. In a preliminary randomized trial, results suggested a very high degree of feasibility and acceptability of the program, and greater improvements in transition readiness for high school students and greater college adjustment for post-high school students, compared to those in a waitlist condition. However, the authors caution that transition interventions may not be sufficient if provided in isolation, as mental health, behavioral, and sociocommunicative difficulties can moderate treatment effects. Empirical support is indeed growing for a host of interventions that aim to improve the transition planning experience post-high school. Some interventions focus primarily on educator and parent coaching (e.g., COMPASS) [Ruble, McGrew, Snell-Rood, Adams, & Kleinert, 2019], on transition planning (e.g., BOOST-A) [Hatfield, Falkmer, Falkmer, & Ciccarelli, 2018], or on preparing for competitive employment (e.g., Project SEARCH Plus ASD) [Wehman et al., 2019]. Additional evidence is likely needed to improve the situation beyond the autistic individual, such as the capabilities of the target contexts (e.g., colleges, employer setting) to create more accepting environments [Accardo et al., 2019; Nicholas et al., 2017; Wehman et al., 2014], and on ensuring that multiple service systems are involved (e.g., health, vocational, education, community and social services) [Baker-Ericzén, Brookman-Frazee, & Brodkin, 2018].

There are limitations to this research. First, this study was based on a convenience sample, and solely on caregiver report. Recent qualitative work with autistic young people via self-report portray positive experiences during the transition to adulthood, such as the development of a sense of identity and autonomy in the face of challenge [Cribb, Kenny, & Pellicano, 2019], and research that only uses parent report can fail to take this first-person perspective. Our results should be considered through the lens of the caregiver who is interpreting service experiences based on their understanding of their child's needs. It is possible that autistic young adults, especially if they are nonverbal and have greater difficulty expressing their needs to their caregivers, may have different service priorities. Further, it will be important for future research to consider whether caregiver levels of stress and burden may impact their perception of priority needs for their child. For example, parents who are highly distressed may prioritize services for their child that may alleviate their own stress rather than solely benefit their child. Second, our measurement of service need, receipt and activity was based on largely dichotomous options, which does not consider that quality of these experiences when they occur. Research and evaluation of service experience needs to be characterized in terms of the quality of the engagement with services. Third, we do not know whether school for those under 21 years of age involved a high school or postsecondary (e.g., college or university) setting. Fourth, although this study shows that individuals do indeed lose services, we do not know what predicts this loss of service.

The current study highlights that transitional risks continue to exist for autistic young adults. Future research underscoring nuanced and complex interactions among individual and contextual factors are needed, especially in ways that take into account multiple perspectives and the changing policy landscapes that exist around emphasizing successful outcomes for autistic adults [Sosnowy et al., 2018]. The rates reported in this sample also beg the question: "What percentage of young adults losing structured weekday activity is acceptable?" This is a transition period that we can expect and that should be planned for. Not having structured weekday activities is a major risk factor for poor quality of life. This is wholly preventable and is crucial to invest in. We must attend to the daily activities for people as they transition out of school, and target efforts toward understanding the one-third of people without activities to fulfill our obligations as a society to include them.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table S1. Comparison of Demographic, Clinical, and Services Variables by Respondent Status.