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In Memoriam: Dr. Bruce McCreary

Author

Patricia Minnes

Department of Psychology,
Queen's University,
Kingston ON

Correspondence

minnesp@queensu.ca

Keywords

Bruce McCreary, obituary, intellectual and developmental disabilities, dual diagnosis, university education

Dr. Bruce McCreary whose entire career was devoted to working with individuals with developmental disabilities and their families passed away at Kingston General Hospital on November 15, 2017 at the age of 78. Dr. McCreary was raised on a farm near Smiths Falls, Ontario, and he attributed his career path to a summer job working at Rideau Regional Centre where many years later he became Clinical Director. Bruce completed his medical and core Psychiatry training at Queen's University followed by graduate work in Child Psychiatry and Mental Retardation at the University of Western Ontario and at the Mental Retardation and Human Genetics Kennedy-Galton Centre in St. Alban's England.

Bruce was committed to his work in the field of developmental disabilities and conducted clinics in Kingston across eastern Ontario for 50 years. At the same time, Bruce was active in work at Queen's University as a professor in the Department of Psychiatry. In 1977, he established the Division of Developmental Disabilities in the Department of Psychiatry. By 1995, the Division had grown to include social work, psychology, rehabilitation, law, genetics, nursing & family medicine. Today, the Queen's Division of Developmental Disabilities is only one of two across Canada.

Over the years, Bruce held a number of positions including:

1990–1993	Director of Research: Department of Psychiatry Queen's University
1995–2002	Director: Neuropsychiatric Genetics Clinic Onwanada
1977–2003; 2006–2010	Chair: Division of Developmental Disabilities Queen's University
1985–1993	Founding Chair: Queen's Developmental Disabilities Consulting Program
1974–1977	Administrator: L. S. Penrose Centre/ Ongwanada
1968–1974	Director of Treatment and Training: Kingston Psychiatric Hospital
1986–2010	Consulting Psychiatrist: Ongwanada, Rideau Regional Centre, Providence Continuing Care Mental Health Services; Kingston General Hospital; Hotel Dieu Hospital and Peterborough Regional Health Centre.

Bruce was as devoted to teaching as he was to his clinical work. Indeed, he continued teaching medical students as a Professor Emeritus until only a few months before his death. He gave many presentations at conferences over the years and authored a number of publications including the following:

McCreary, B. D., & Jones, J. (2013). *Intellectual disabilities and dual diagnosis. An interprofessional clinical guide for healthcare providers.* Kingston, ON: McGill-Queen's University Press.

McCreary, B. D., & Rischke, A. (2013). Intellectual disability and stigma: An Ontario perspective. *Clinical Bulletin of the Developmental Disabilities Division, 24*(3), Autumn.

McCreary, B. D., & Rischke, A. (2012). Welcome to our community: Social inclusion for persons with intellectual and developmental disabilities: An essay. *Clinical Bulletin of the Developmental Disabilities Division, 23*(1), Spring.

McCreary, B. D., Jones, J., & McQueen, M. (2012). Managing the challenge of "challenging behaviour" for persons with intellectual disabilities. *Clinical Bulletin of the Division of Developmental Disabilities Division, 23*(2 & 3), Summer Fall.

McCreary, B. D., & Jones, J. (2009). *Developmental neuropsychiatry: Teaching medical residents about developmental disabilities.* In J. S. Leverette, G. S. Hnatko, & E. Persad (Eds.), *Approaches to postgraduate education in psychiatry in Canada: What educators and residents need to know* (pp. 199–209). Ottawa, ON: Canadian Psychiatric Association.

McCreary, B. D. (2005). *Developmental disabilities and dual diagnosis. A guide for Canadian psychiatrists.* Kingston, ON: Queen's University Developmental Consulting Program, Queen's University.

McCreary, B. D. (2001). Developmental neuropsychiatry. In B. D. McCreary, P. Peppin, & B. Stanton (Eds.), *Catalysts for university education in developmental disabilities* (pp. 97–114). Kingston, ON: Developmental Consulting Program, Queen's University.

Peppin, P., McCreary, B. D., & Stanton, B. (Eds). (2001). *Catalysts for university education in developmental disabilities.* Kingston, ON: Developmental Consulting Program, Queen's University.

Dr. McCreary also was the recipient of several awards including:

2009	NADD-Ontario Chapter Recognition Award for lifetime contributions to the field of developmental disabilities
2008	June Caldwell Award recognizing outstanding contribution in support of people with developmental disabilities
2003	Canadian Psychiatric Association Roberts Award for his clinical work and leadership in the field of developmental disabilities.
1989	Hull-Roeher Award, Ontario Chapter, American Association on Mental Retardation (now Ontario Association on Developmental Disabilities) for outstanding contributions to Education, Research and Service in the field of developmental disabilities

To quote just a few of Bruce's colleagues, friends, students and family attending a memorial gathering held at the Ongwanada Community Resource Centre:

"Bruce shared wisdom without arrogance and expertise without vanity; he mentored without intimidation and led fearlessly without dominance."

"At first glance Bruce appeared to be an unassuming and kind man who gave everyone his time and utmost attention; however he also was a visionary and relentless advocate."

"His passion for the field of developmental disability was contagious and his desire to share his knowledge was inspiring. Bruce left a deep impression on most to strive harder, do better and always fight for the less fortunate."

"He will continue to inspire us for many years to come."

Bruce is survived by his children Rick (Lois), Janet (Bernard), Alison (Martin) and Andrew (Paula) and five grand children. Sadly, Bruce's family is also mourning the loss of their mother and Bruce's wife, Carolyn who passed away only a short time after Bruce on February 10, 2018 .

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Health and Health Care Utilization of Manitoba Children in Care With and Without Developmental Disabilities: A Population-Based Comparative Study

Authors

Dustin Heinrichs,[1]
Shahin Shooshtari,[2]
Marni Brownell,[2]
Rosemary Mills,[2]
Brenda Stoesz[3]

[1] Department of Family Social Sciences, University of Manitoba, Winnipeg MB

[2] Department of Community Health Sciences, Max Rady College of Medicine, University of Manitoba; St.Amant Research Centre, Winnipeg MB

[3] Department of Psychology, University of Manitoba, Winnipeg MB

Correspondence

shahin.shooshtari@umanitoba.ca

Keywords

administrative data,
developmental disabilities,
foster care,
health services use,
health status

Abstract

Background

This study examined health disparities between children with and without developmental disabilities (DD) living in child protective care. We conducted a population-based study of children in care in Manitoba, Canada; 11% were identified with DD.

Method

Using administrative health data, we compared the health status and health services utilization of children in care with (n = 1,212) and without (n = 2,424) DD, matched by age, sex, and region of residence, using Generalized Estimating Equation (GEE) regression modelling.

Results

Among children in care, those with DD were significantly more likely to have a history of mood and anxiety disorders, respiratory illnesses, diabetes, hospital-based dental care, and injury-related hospitalizations, and made more ambulatory physician visits compared to those without DD.

Conclusions

Compared to their counterparts in care, those with DD are more likely to have health problems and use health services. Recommendations are made for further research.

Children with developmental disabilities (DD) are at great risk of being removed from their biological family of origin and placed *in care* of another family (e.g., foster care) or alternative living arrangement (Shooshtari et al., 2016). Manitoba has the highest rate of children *in care* in Canada (Canadian Child Welfare Research Portal, 2011). Children are often placed in care because of concerns related to abuse, family death or conflict, or emotional problems (Brownell et al., 2011). Those with DD are overrepresented in the in-care population (Brownell et al., 2015). To date, however, children with DD and children in care have typically been studied as non-overlapping groups, with the result that little is known about the health status and health care utilization specifically of *children in care with developmental disabilities*. The primary goal of the present population-based study was to examine health and health care use of children in care with DD to determine whether health disparities are more pronounced for those with DD compared to their counterparts without DD.

As a group, children in care are more likely to have impairments and chronic illnesses that require specialized services (see Christian & Schwarz, 2011), psychosocial problems

(Altshuler & Poertner, 2003; Simms, 1989), and respiratory illnesses leading to hospitalizations (Brownell et al., 2011) than those not in care. Children in care are also more likely to be overweight and obese (Hadfield & Preece, 2008), putting them at greater risk for developing diabetes (Altshuler & Poertner, 2003) compared to the general population of children. Children in care also lack preventative dental care, increasing the likelihood of hospital-based dental treatment (Kling, Vinnerljung, & Hjern, 2016; Melbye, Chi, Milgrom, Huebner, & Grembowski, 2014). Children with DD (Shooshtari et al., 2014) and children in care (Brownell et al., 2011) are also at high risk for injury. Despite the high number of physician visits and hospital admissions, children with DD (Shooshtari et al., 2016) and children in care (DiGiuseppe & Christakis, 2003) lack continuity of care.

Children with DD are also an at-risk group; they are more likely to be diagnosed with respiratory illnesses and depression, to be hospitalized due to injury (Shooshtari et al., 2014, 2016), and to be obese and have diabetes (Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010) than those without DD. Children with DD have more ambulatory physician visits (Lee & Chen, 2012), and are more likely to be admitted to hospital on more occasions, for longer durations, and for a broader range of clinical diagnoses (Gallaher, Christakis, & Connell, 2002; Williams et al., 2005), and to be seen by specialists (Schieve et al., 2012) than children without DD. Children with DD are less likely than those without DD to receive preventative dental care (Chi, Momany, Kuthy, Chalmers, & Damiano, 2010), and more likely to be admitted to hospital for dental treatment (Slack-Smith et al., 2009). Children with DD are also at high risk for injury (Shooshtari et al., 2014). Moreover, despite the high number of physician visits and hospital admissions, children with DD lack continuity of care (Shooshtari et al., 2016). Factors contributing to health disparities in people with DD include health-damaging behaviours, inadequate access to health services, and motor impairments (Ouellette-Kuntz, Garcin, Lewis, Martin, & Holden, 2005); other factors may include out-of-home placement and vulnerability to maltreatment (see Sullivan & Knutson, 2000). Thus, being placed in care may compound the health disparities experienced by children with DD, making children with DD a particularly vulnerable subgroup of those in care. The purpose of the present study was to determine whether health disparities are greater for this subgroup.

Toward this end, the aim of the present study was to examine differences in health status and health services utilization of Manitoba children in care with DD and without DD. The objectives were to (1) describe the demographic and socioeconomic characteristics of the two groups, and compare the two groups with respect to (2) physical and mental health status, and (3) health care utilization patterns. An enhanced understanding of disparities in health and access to health services experienced by children in care with DD may help program providers and planners better meet the needs of these children.

Methods

Study Design and Setting

A retrospective cohort study was conducted using multiple years of administrative health data collected in Manitoba, a province of Canada with a population of 1.2 million (Statistics Canada, 2012). Manitoba provides publicly funded universal health care to its residents via five regional health authorities (RHAs). Region of residence was considered in this study as prior research shows regional variations in access to health services (Brownell et al., 2015).

Data Sources

Data were obtained from databases contained in the Manitoba Population Research Data Repository maintained by the Manitoba Centre for Health Policy (MCHP). Each person registered with the provincial health department is assigned a nine-digit Personal Health Identification Number (PHIN). We used de-identified and scrambled PHINs for data linkage to protect confidentiality without losing track of individuals over time and across various databases in this study. Eighteen years of health and non-health administrative data (1995–2012) were linked to identify the study cohort. The databases used for the present study were: (1) Hospital discharge abstracts; (2) Physician claims; (3) Drug Program Information Network file; (4) Enrolment data from Manitoba Education and Training; (5) Manitoba Fetal Alcohol Spectrum Disorder (FASD) Centre; (6) Manitoba Population Registry (2012); and (7) Child and Family Services Information System (CFSIS) data set. Canadian Census data (2011) were used to determine neighbourhood income quintiles. Three years of data (2009–2012) from the health databases were used to examine health status and access to health care services.

Study Population

The study population consisted of children (aged 0–17 years in 2012) in care. Children "in care" were those who had been removed from the care of their original families because of a situation where authorities have deemed their family unable or unfit to look after them properly (Brownell et al., 2011). In this study, children "in care" were identified based on the Child and Family Services Information System (CFSIS) data set from Manitoba Department of Family Services. The study population (i.e., children in care) was then divided into two groups: those in care with a DD and those in care without a DD.

The cohort of children in care with DD consisted of those who met at least one of the following criteria: (1) received special education funding due to multiple handicaps or autism spectrum disorder based on information obtained from the enrolment data; (2) presence of a diagnostic code for DD in the hospital discharge abstracts or physician claims; or (3) presence of a diagnostic code for an alcohol-related disorder in the Manitoba FASD Centre database (as per Shooshtari, Martens, Burchill, Dik, & Naghipur, 2011). The comparison group consisted of children in care who did not meet the criteria for DD. Each child with a DD was matched with two children of the same age, sex, and region of residence in the comparison group, which allowed minimization of the influences of these factors as potential confounders (see Fransoo et al., 2013; Shooshtari et al., 2014). Of the 1,212 children with DD in care, 1,202 (99.2%) were matched on a ratio of 1:2 (two children in care without DD for every child in care with DD) based on exact year of birth, sex, and region of residence. As it was not possible to match the remaining 10 children with DD in care with children on the same exact birth year, they were matched as closely as possible on birth year plus or minus one year, but the exact match on sex and place of residence.

Study Measures

Characteristics of children in care with and without DD. The two study groups were compared with respect to several personal and in-care characteristics: (1) *Child age and sex*, with age defined as time in years from birth to 2012 and sex as biological male or female status; (2) *Child socioeconomic status (SES)*, measured using 2011 Canada Census neighbourhood income data and calculated by dividing the total population into income quintiles based on mean household income, with higher values reflecting higher incomes (Fransoo et al., 2009); (3) *Child place of residence*, described as the health region in which the child resided; and (4) *In-care characteristics*: the number of episodes and the duration of children's placement in care, using 18 years of data (1995–2012) from the CFSIS dataset. The number of episodes in care was defined as the number of times that a child entered or re-entered into care over their time. Children placed in care for fewer than seven days were excluded from the analyses. Duration of care was examined in years.

Physical and mental health status. Three measures of child health were obtained: (1) *Total Respiratory Morbidity* (TRM), defined as the proportion of population in each study group that had a respiratory illness (Fransoo et al., 2009); (2) *Diabetes*, defined as at least one hospitalization with a diabetes diagnosis, or at least two physician visits with a diabetes code, or filled two or more prescriptions for diabetes medication; (3) *Mood or anxiety disorders*, defined as meeting at least one of the following criteria: (a) one or more hospitalizations with a diagnosis of depressive disorder, affective psychosis, neurotic depression, or adjustment reaction; (b) one or more hospitalizations with a diagnosis for anxiety disorders AND one or more prescriptions for an antidepressant or mood stabilizer; (c) at least one physician visit with a diagnosis for depressive disorder, affective psychoses, or adjustment reaction; or (d) one or more physician visits with a diagnosis for anxiety disorders AND one or more prescriptions for an antidepressant or mood stabilizer (Fransoo et al., 2009; Martens et al., 2010).

Health service utilization. Children's use of health care services was assessed by four measures: (1) *Continuity of care*, assessed for children with at least three physician visits over a specified period (2009–2012). Children who visited the same physician for more than 50% of visits were classified as having continuity of care, whereas those who visited the same physician for 50% or less of their visits to physicians were classified as not having continuity of care. (2) *Total ambulatory physician visits*, assessed as the number of ambulatory visits to general practitioners and specialists, including visits in offices and walk-in clinics, homes, personal care homes, and outpatient departments over three years (2009–2012). (3) *Injury-related hospitalizations*, measured as admissions of more than one day coded in the hospital abstract records over three years (2009–2012). (4) *Hospital-based dental care*, indicated by a diagnostic code for procedures that took place in a hospital. Children with dental cavities and periapical abscess without sinus, and with an identified surgical procedure such as tooth restoration were classified as those who received hospital-based dental care. A list of ICD codes used to define the above listed measures is provided in Appendix A.

Data Analysis

The proportion of children with TRM, diabetes, and mood and anxiety disorders were computed to estimate prevalence at the population level. We also estimated the rates of hospitalized dental care, continuity of care, and injuries. The estimates for the two study groups were compared using Generalized Estimating Equation regression modelling, taking matching into consideration. We used the relative risk (RR) and 95% confidence intervals to determine if the observed differences in prevalence estimates were statistically significant. Comparisons between the study groups were conducted using paired *t*-tests for number of episodes and duration in care, and total ambulatory physician visits. Data analyses were performed using SAS software, version 9.1 (SAS Institute Inc., 2004).

Ethics

This research was approved by the University of Manitoba Research Ethics Board.

Results

Characteristics of Children in Care With and Without DD

As Table 1 shows of the 8,830 children living in care in 2012 for more than 7 days, 13.73% (1,212) had DD. The mean age of children with DD was 10.57 years (*SD* = 4.44), and that of the comparison group was 10.56 years (*SD* = 4.41). Table 1 shows the distribution of the study groups by age, sex, place of residence, and income quintile. Due to matching, age, sex, and regional distribution of the two study groups are similar. However, as shown in Table 1, a smaller proportion of children in care with DD than those in care without DD were living in neighbourhoods with higher income. Overall, the two groups differed in terms of their neighbourhood income level [$\chi^2 = 69.93$, $df = 5$, $p < .0001$].

As summarized in Table 2 (see page 10), children with DD were in care for more days than children in the comparison group [$t(2{,}217.1) = -12.59$, $p < .0001$]; however, the average number of episodes was similar between groups [$t(2{,}356.5) = 0.38$, $p = .71$].

Physical and Mental Health Status of Children in Care With and Without DD

Three indicators were used to measure and compare physical and mental health status between the study cohort and the matched comparison group. As summarized in Table 3, children in care with DD had a higher risk of respiratory illnesses (RR = 1.20, 95% CI: 1.05, 1.37, $p = 0.0082$), diabetes (RR = 2.13, 95% CI: 1.21, 3.75, $p = .0092$), and mood or anxiety disorders (RR = 1.88, 95% CI: 1.42, 2.49, $p < .0001$) than did the children in the comparison group.

Health Service Utilization by Children in Care With and Without DD

As shown in Table 3 (see page 11), the average number of ambulatory physician visits for children with DD ($M = 36.90$, $SD = 47.73$) was significantly higher than that found for the comparison group [$M = 23.20$, $SD = 17.28$; $t(1{,}285.2) = 9.23$, $p < .0001$]. Children with DD were significantly more likely than those in the comparison group

Table 1. Distribution of Study Populations by Age, Sex, Health Region of Residence, and Income Quintile

	Children in Care With Developmental Disability (N = 1, 212)		*Children in Care Without Developmental Disability (N = 2,424)*	
Characteristics	*n*	%	*n*	%
Sex				
Male	760	62.71	1,520	62.71
Female	452	37.29	904	37.29
Age				
0–2	55	4.54	110	4.54
3–5	151	12.46	296	12.21
6–8	185	15.26	373	15.39
9–11	216	17.82	456	18.81
12–14	314	25.91	633	26.11
15–17	291	24.01	556	22.94
Health region of residence				
Interlake-Eastern	92	7.59	184	7.59
Northern	63	5.20	126	5.20
Southern	53	4.37	106	4.37
Prairie Mountain	61	5.03	122	5.03
Winnipeg	943	77.81	1,886	77.81
Income quintile				
NF	659	54.37	959	39.98
Lowest quintile Q1	327	26.98	897	37.00
Q2	106	8.75	270	11.14
Q3	62	5.12	135	5.57
Q4	46	3.80	127	5.24
Highest quintile Q5	12	0.99	26	1.07

Note: NF = data "Not Found" could be due to multiple reasons; the most likely reason in this study is that the postal code is associated with the Child and Family Services (CFS) Office.

to have a history of injury-related hospitalization (RR = 2.36; 95% CI: 1.38, 4.03, *p* = .0016) and hospital-based dental care (RR = 1.74; 95% CI: 1.28, 2.38, *p* = .0004); however, the two study groups had comparable rates of continuity of care (OR = 0.89, 95% CI: 0.75, 1.05, *p* = .1726).

Discussion

The present study had three objectives. These objectives were met by examining retrospective linked health and non-health administrative data for a population-based cohort of Manitoba children in care with and without DD. The first objective was to describe demographic and socioeconomic characteristics of children in care with and without DD. More than 3% of all Manitoba children were identified as being in care for more than seven days in 2012, and nearly 14% of these children in care were identified with DD. Manitoba has one of the highest rates of children in care among Canadian prov-

Table 2. Distribution of Duration In Care and Number of In Care Episodes

	Children in Care With Developmental Disability		*Children in Care Without Developmental Disability*	
Characteristic	*n*	%	*n*	%
Duration in care (years)				
< 1	29	2.39%	137	5.65%
1	84	6.93%	322	13.28%
2	89	7.34%	283	11.67%
3	102	8.42%	279	11.51%
4	111	9.16%	246	10.15%
5	98	8.09%	213	8.79%
6	81	6.68%	173	7.14%
7	91	7.51%	168	6.93%
8	81	6.68%	107	4.41%
> 9	446	36.80%	496	20.46%
Average number of days in care	2,789.46 (*SD* = 1,628.27)		2,090.83 (*SD* = 1,472.18)	
Number of episodes				
1	466	38.45%	976	41.26%
2	468	38.61%	801	33.04%
3	147	12.13%	357	14.73%
4	67	5.53%	167	6.89%
5 or more	64	5.28%	123	5.07%
Average number of episodes in care	2.06 (*SD* = 1.32)		2.07 (*SD* = 1.28)	

inces and territories (Canadian Child Welfare Research Portal, 2011). Compared to children without DD, children with DD were in care significantly longer per episode, suggesting that they either enter care earlier, or less likely to return to their family of origin than children without DD. Nearly one third of all children in care were residing in the lowest income neighbourhoods. Living in poverty increases the risk for a number of health problems and adverse life events, particularly for children with DD (Emerson, 2007, 2015).

The second objective was to examine the health status of children in care with and without DD. Children in care with DD had significantly higher rates of respiratory morbidity, diabetes, and mood or anxiety disorders than those without DD. Higher respiratory morbidity in children with DD may be attributed to greater susceptibility to respiratory infections because they often have physical abnormalities, immune dysfunction, and/or gastro-esophageal results that increase susceptibility to infections (Doull, 2001; Ram & Chinen, 2011). Higher prevalence of diabetes among children in care with DD than without DD is consistent with previous research indicating that children with DD have an increased risk of diabetes (Beange, Lennox, & Parmenter, 1999; Fujiura, Fitzsimons, Marks, & Chicoine, 1997; Rimmer, Braddock, & Fujiura, 1994).

Similar to previous findings for adults with DD (see Cooper et al., 1996), children in care with DD were more likely to have a history of mood or anxiety disorders than those in the comparison group. Depression is linked to a variety of adverse outcomes including self-injurious behaviours in children with DD (Cooper et

Table 3. Health Indicators by Study Group

Health Indicator	*Children With Developmental Disability (%)*	*Matched Comparison Group (%)*	*Odds Ratio (95% CI)*	p*-value*
Total respiratory morbidity (TRM)	45.54	41.17	1.05 (1.05–1.37)	.0082
Diabetes	1.40	0.66	2.13 (1.21–3.75)	.0092
Mood and anxiety disorders*	19.76	11.21	1.88 (1.42–2.49)	< .0001
Continuity of care	37.92	40.75	0.89 (0.75–1.05)	.1726
Injury related hospitalizations	1.90	0.83	2.36 (1.38–4.03)	.0016
Hospital-based dental care	7.51	4.13	1.74 (1.28–2.38)	.0004

*Note: *Consistent with the Manitoba Centre for Health Policy (MCHP) definition of mood and anxiety disorders, only children over the age of 10 were included in the analyses.*

al., 2009; Hardan & Sahl, 1999). Psychotropic medications have been prescribed to manage self-injury and other challenging behaviours in this population; however, little is known about the effectiveness of these medications for this purpose (Matson & Neal, 2009), which may increase risk for adverse side effects. In addition, studies in other jurisdictions found that although children whose placements change while in care, or leave and then re-enter care have a higher rate of mental health services utilization, they are not receiving appropriate treatment (Leslie, Hurlburt, Landsverk, Barth, & Slymen, 2004; Simms, Dubowitz, & Szilagyi, 2000). Examining placement change, and reviewing the level of family support and personal coping skills of children in care with DD is necessary, as these factors may mitigate symptoms associated with mood or anxiety disorders (Essau, Conradt, Sasagawa, & Ollendick, 2012; Kochenderfer-Ladd & Skinner, 2002; Weiss, 2002).

The third objective was to examine the utilization of health services in the study population. There were significant disparities in physician visits and injury-related hospitalizations for children with DD compared to those without DD, but no differences with respect to continuity of care. Poor health outcomes for children in care are often attributed to previous exposure to parental substance abuse and mental illness, poverty, and family and neighbourhood violence (see Curtis, 1999), and the trauma of separation from their families (see Christian & Schwarz, 2011; Clausen, Landsverk, Ganger, Chadwick, & Litrownik, 1998), and the unmet health care needs of may continue to go unaddressed even after placement (Deutsch & Fortin, 2015; Simms et al., 2000; Takayama, Wolfe, & Coulter, 1998). This may be particularly true for children in care with DD. Despite high utilization of physician services, the complex health care needs of children with DD often remain unmet (Leslie et al., 2003) because of placement instability and the fragmented health systems (Simms et al., 2000), and contribute to a lower rate of primary preventive care (Kortenkamp & Ehrle, 2002).

The finding of more hospital-based dental care among children in care with DD also is consistent with previous research (e.g., Shooshtari et al., 2015). Hospital settings are often the preferred or necessary location for treating oral health issues in children with DD because they exhibit more behavioural problems or have more advanced tooth destruction (Balogh, Hunter, & Ouellette-Kuntz, 2005; Enever, Nunn, & Sheehan, 2000; Melbye, Huebner, Chi, Hinderberger, & Milgrom, 2013; Schneiderman, Smith, & Palinkas, 2012; Shooshtari et al., 2015). Future studies should explore reasons for unmet dental needs in persons with DD.

The present study is the first population-based study of health and health care utilization patterns of Manitoba children in care with DD using information that cannot be obtained from other provincial or national sources. However, the data lack information on several personal (e.g., health-related behaviours) and environmental (e.g., family dynamics) factors that may provide insight into children's overall health and well-being and longer-term health outcomes. Although we did control for the effects of age, sex, and place of residence in our analyses, we did not control for the effects of neighbourhood income level. Given the fact that a smaller proportion of children with DD than those without DD were living in neighbourhoods with higher income, this factor might have helped to explain some of the disparities in health and utilization of health services observed between the two study groups. Another limitation of the study relates to the diagnostic codes used to identify the selected health conditions and outcomes. The ICD codes present are not definitive clinical diagnoses; rather they are indicators that services for particular issues were utilized. In spite of these limitations, our study findings can be used by those involved in planning and provision of health and social services to children in care in Manitoba and in other jurisdictions to improve the health and the quality of care that the children in care with and without DD receive.

Key Messages From This Article

People with disabilities. You deserve to be healthy and have access to healthcare that you need, even if you are not cared for by your own family.

Professionals. Children in care with developmental disabilities are at a greater risk for a number of health conditions and injuries compared to other children in care. You need to be aware of specific needs of children in care with developmental disabilities.

Policymakers Policy to ensure health and safety of children in care with developmental disabilities is necessary to prevent negative health outcomes such as mental illness and unnecessary use of health services.

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Appendix A: ICD Codes

Total Respiratory Morbidity (TRM): ICD-9-CM codes 466, 490, 491, 492, 493, 496; ICD-10-CA codes J20, J21 or J40-J45

Diabetes: ICD-9-CM code 250; ICD-10-CA codes A10 (Anatomical Therapeutic Chemical [ATC]) and E10-E14

Mood or anxiety disorders. ICD-9-CM codes 296, 309, 311 (depressive disorder, affective psychoses, or adjustment reaction); ICD-9-CM code 300 (anxiety disorder) AND ATC codes N03AB02, N03AB52, N03AF01, N05AN01, N06A; ICD-10-CA codes F31, F32, F33, F34.1, F38.0, F38.1, F41.2, F43.1, F43.2, F43.8, F53.0, F93.0 (depressive disorder, affective psychosis, neurotic depression, or adjustment reaction); ICD-10-CA codes F32.0, F34.1, F40, F41, F42, F44, F45.0, F45.1, F45.2, F48, F68.0, F99 (anxiety disorders) AND ATC codes N03AB02, N03AB52, N03AF01, N05AN01, N06A (antidepressant or mood stabilizer)

Injury-related hospitalizations. ICD-10-CA codes within the categories of transportation accidents (V01-V79), falls (W00-W19), exposure to mechanical forces (W20-W64), accidental drowning and submersion (W65-W74), other accidental threats to breathing (W75-W84), exposure to electric current, radiation and extreme ambient air temperature or pressure (W85-W99), exposure to smoke, fire and flames (X00-X09), contact with heat and hot substances (X10-X19), contact with venomous plants and animals (X20-X29), exposure to forces of nature (X30-X39), accidental poisoning and exposure to noxious substances (X40-X49), overexertion, travel and privation (X50-X57), exposure to other and unspecified accidental factors (X58,X59), intentional self-harm (X60-X84), assault, including neglect and abandonment and other maltreatment syndromes (X85-Y09), event of undetermined intent (Y10-Y34), legal intervention and operations of war (Y35 and Y36).

Hospital-based dental care. ICD-10-CA codes of K02 (dental cavities) and K04.7 (periapical abscess without sinus), and with an identified surgical procedure (Canadian Classification of Health Interventions [CCI]) codes of 1.FE.57.JA (tooth extraction), 1.FF.56 (removal of foreign body, root of tooth), 1.FF.89 (excision total, root of tooth), 1.FE.89 (excision total, tooth), 1.FE.29 (tooth restoration), 1.FE.53.JA-RV (implantation of internal device, tooth), 1.FF.59.JA (destruction, root of tooth), 1.FD.52 (gingival drainage), 1.FE.87.JA-H (excision partial, tooth), 1.FF.53 (implantation of internal device, root of tooth), 1.FF.80 (repair, root of tooth), and 1.FF.87 (excision partial, root of tooth).

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Risk Factors for Complex Special Needs Among Male Children Seeking Mental Health Services

Authors

Alshaba S. Billawala,[1]
Chloe A. Hamza,[2]
Shannon L. Stewart[1]

[1] Faculty of Education, Western University, London ON

[2] Ontario Institute for Studies in Education, University of Toronto, Toronto ON

Correspondence

chloe.hamza@utoronto.ca

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Abstract

Children and youth with complex special needs (CSN) present with mental health issues and experience diverse developmental and physical health challenges, often requiring care from several service sectors throughout their lifespan. Despite the chronic service needs of children with CSN, little is known about the factors that contribute to the need for additional financial support to care for these children. To address this gap in the literature, the present study sought to identify risk factors present amongst children and youth seeking mental health services whose families were referred for complex special needs funding in the province of Ontario, Canada. Using data collected from 1,020 male children in Southwestern Ontario using the interRAI Child and Youth Mental Health assessments, the present study examined whether children referred for CSN funding differed from children in clinical care who were not referred for CSN funding. Binary logistic regression analyses revealed that impairments in family functioning (OR = 6.206, CI: 1.827-20.551) were most strongly associated with CSN funding referral. Child challenges in completing activities of daily living were also associated with CSN referral, but this effect was small (OR = 1.063, CI: 1.020-1.100). Implications for decisions around funding allocation with respect to CSN funding in Ontario are discussed.

Many children and youth (hereafter referred to as children) seeking mental health services in Ontario require specific time-limited interventions to improve or resolve their symptoms (Clark, O'Malley, Woodham, Barrett, & Byford, 2005). A small percentage, however, (approximately 10% of those referred for mental health services) present with increased complexity (Epstein, Kutash, & Duchnowski, 2004; Reid et al., 2011). The expense for caring for these children accounts for a disproportionate portion of health care costs, as these children require "episodic, chronic, and ongoing care" from multiple service sectors (Reid et al., 2014; Stewart & Hirdes, 2015). Although the term complex special needs (CSN) has been used to describe these children in Ontario, a variety of terms have been used in the literature, including: multiple disadvantaged, technology dependent, and medically complex (Cohen et al., 2011; Davidson, Bunting & Web, 2012; Day, Davis & Bidmead, 2002; McArthur & Faragher, 2014; Rosengard, Laing, Ridley, & Hunter, 2007).

Of particular interest is the subset of children with complex special needs (CSN), due to mental health problems, who are referred for specialized funding due to the extensive resource needs of the child (Day et al., 2002; Robinson, Jackson, & Townsley, 2001; Tahhan, St. Pierre, Stewart, Leschied, & Cook, 2010; Teare, 2008). According to the Ministry of Children and Youth Services (n.d.) in Ontario, children with CSN who may be eligible for CSN funding are children who: (1) are under the age of 18 and are in need of long term and/or continuous specialized supports, (2) have two or more different special needs and require integration of services across different sectors (e.g., mental health, disability services, education), and (3) have needs based on a variety of comorbid conditions, including: mental health diagnoses, intellectual, physical and developmental disabilities, and chronic, terminal and severe physical health illnesses. Although families may be eligible to apply for funding, provincial governments cannot provide funding to every family and policy makers have struggled to identify which families are most in need of this envelop of specialized funding (Burnside, 2012; Robinson et al., 2001; Spratt, 2010). These difficulties in funding allocation underscore the need for a system that is able to better distinguish families most in need of additional funds. One way to identify families with the greatest need for CSN funding is through an examination of the risk factors present among children who have been referred for CSN funding.

Risk Factors for CSN Funding

Identifying risk factors that contribute to a high needs presentation (and need for additional financial assistance to meet service needs) can serve to inform provincial-level decisions around service allocation. Although research on which families are referred for CSN in Ontario is non-existent, several potential risk factors may be associated with increased need for funding. For example, the presence of mental health concerns and/or physical, intellectual or developmental disabilities (e.g., autism, Down syndrome, spina bifida; Burnside, 2012; Carnaby, 2007; Coller et al., 2016; Kennedy et al., 2007; Tean, 2014; Vig, Chinitz, & Shulman, 2005) may be associated with increased resource need, and thus the demand for more extensive financial support. Moreover, children with more severe disabilities may also experience challenges with daily activities (e.g., bathing, toileting, mobilizing), and be more dependent upon caretakers and equipment, making these children extremely high need (Department of Health, 2004; Goddard, Davidson, Daly, & MacKey, 2008; Pastor, Reuben, & Loeb, 2009; Roberts & Lawton, 2001; Rosengard et al., 2007). In addition, family dysfunction (e.g., presence of parental illness/disability, poor parent-child interactions, and lack of supports) has been known to be predictive of poor outcomes for children, such as psychiatric illnesses and developmental delays (Hewitt-Taylor, 2005; Landy & Tam, 1998; McArthur & Faragher, 2014). Moreover, these families often report lacking the support they need to cope with increased responsibility, emotional exhaustion, heightened distress, and reduced quality of life (Brown, Geider, Primrose, & Jokinen, 2011; Carnevale, Alexander, Davis, Rennick, & Troini, 2006; McArthur & Faragher, 2014; Robinson et al., 2001; Webb, Bunting, & Shannon, 2014), placing these children at greater risk for foster or residential care, treatment-based facilities and other institutions (Burnside, 2012; Stewart, Hassani, Poss & Hirdes, 2017; Tahhan et al., 2010).

The Current Study

Despite increased research on children with CSN, there is a paucity of research on understanding which families of children with CSN are referred for additional funding in Ontario. Moreover, current studies are limited by individual surveys that focus on particular areas of risk (Davidson et al., 2012). Although studies like these elucidate the impact of particular risk factors, researchers have recommended the need for comprehensive assessment tools that can objectively identify “multiplicity of problems” (Carnaby, 2007; Clark et al., 2005; Spratt, 2010; Stewart et al., 2017). To address these gaps in the literature, we examined which risk factors (i.e., activities of daily living [ADL], mental illness comorbidity, physical/medical illness, and impairments in family functioning) may assist in predicting CSN funding referrals by comparing children seeking mental health services who were referred for CSN funding to children seeking mental health services not referred for specialized CSN funding. Although the present study was largely exploratory, it was hypothesized that children referred for CSN funding would present with reduced capacity for completing ADL, increased physical/medical illness and mental illness comorbidity, and more impairments in family functioning relative to children who were not referred for this specialized funding.

Method

Participants

The present sample consisted of 1,020 male children between 4–18 years (*M*age = 10.96, *SD* = 3.43) who completed the interRAI Child and Youth Mental Health or Child (ChYMH) or Child and Youth Mental Health - Developmental Disability (ChYMH-DD) assessment in Southwestern Ontario between October 2012 and August 2015. Of the 1,020 participants, 44 were specifically referred to the Ministry of Children and Youth Services of Ontario by agencies across Southwestern Ontario for CSN funding. Of those youth referred for CSN funding, 30% had a provisional diagnosis of autism at time of treatment intake, and 27% had a provisional diagnosis of a learning or communication disorder. Females were excluded from the present study (N = 10), due to ethical concerns around reporting on the characteristics of small samples (in order to protect participant confidentiality). All participants completed the assessments on a voluntary basis and their quality of care was not impacted if they choose not to participate.

Measures

The two instruments that were utilized were the ChYMH or the ChYMH-DD, which were created by interRAI, a not-for-profit collective of researchers and clinicians from over thirty countries. The ChYMH (Stewart, Hirdes et al., 2015) and ChYMH-DD (Stewart, LaRose et al., 2015) are comprehensive instruments that incorporate information that would typically require multiple assessment tools (e.g., Stewart, Currie, Arbeau, Leschied, & Kerry, 2015; Stewart & Hirdes, 2015). The ChYMH-DD is an adapted version of the ChYMH, specifically for children with intellectual and/or developmental disabilities. At time of intake, assessors completed the ChYMH for children with an IQ above 70, and children with an IQ of 70 or below completed the ChYMH-DD (i.e., all youth had one of the two assessments completed). Trained assessors completed the assessments; these assessors had a diploma or degree in the mental health field, at least two years of clinical experience with children and youth, and had completed a 2.5-day training program for administration of the interRAI ChYMH and ChYMH-DD. The interRAI suite of instruments have strong validity and reliability for children and adults (Phillips et al., 2011; Phillips et al., 2012; Stewart & Hirdes, 2015). The scales used on the ChYMH and ChYMH-DD have been shown to have good internal consistency, as well as well as criterion validity (Stewart & Hamza, 2017; Lau, Stewart, Saklofske, Tremblay, & Hirdes, 2017). In the present study, risk factors for CSN funding assessed using the ChYMH and ChYMH-DD included: activities of daily living, mental health comorbidity, presence of a physical/medical condition, and family functioning.

Activities of Daily Living (ADL) scale. The ADL scale assessed the child's ability to engage in a variety of different daily living tasks (e.g., dressing, bathing, locomotion) on a 6-point scale (0 = *independent* to 6 = *total dependence*). Participants are scored from "0–48" with higher scores indicating greater dependency on others to perform ADL.

Mental illness comorbidity. For the purposes of this study, a mental illness comorbidity variable was created using items measuring different provisional DSM-IV diagnoses (e.g., mood disorder, anxiety disorder, etc.) as indicated by a psychiatrist or physician. This data was then used to create a variable which was coded as: 0 = *no mental illness comorbidity* (if 0 or 1 DSM diagnosis) or 1 = *presence of mental illness comorbidity* (if 2 or more DSM diagnoses).

Physical/medical illnesses. For the purposes of this study, a physical/medical illness variable was created using items on the instruments that inquired about previous medical diagnoses (e.g., asthma, diabetes, epilepsy). This data were then used to create a variable that was coded as 0 = *no physical/medical illness* or 1 = *presence of physical/medical illness.*

Family Functioning Scale (FFS). The FFS evaluates family cohesion, conflict and hostility. It also measures whether or not family members feel overwhelmed by the child's current condition or feel unable or are unwilling to continue caring for the child. Additionally, information regarding the mental health status of the parents, siblings and other close family members is also measured. This scale was treated dichotomously with scores of "0" indicating no difficulties in family functioning and scores greater than 0 indicating the presence of difficulties in family functioning.

Procedure

Clinicians completed the ChYMH or ChYMH-DD instruments using all available sources of information, including direct contact with the family and child, and other service providers and records (e.g., educators and health care clinicians) at time of clinical referral. A majority of the participants completed the instrument when seeking mental health services at one of twenty mental health facilities as typical standard of care (*N* = 976). The children and families who were referred to the Ministry of Children and Youth Services of Ontario for CSN funding (*N* = 44), completed the assessments with a trained assessor after a specialized team had reviewed the referrals. The data collected was approved by the Western University Ethics Review Board (REB: 106415).

Analysis

To examine whether a set of risk factors could be used to predict CSN funding referral, binary logistic regression analyses were used. First, it was examined whether the set of risk factors predicted CSN funding referral using the entire sample. Second, given that the sample size of the CSN group was disproportionately smaller than the non CSN group, we then ran the analysis using an age-and instrument-type matched (ChYMH or ChYMH-DD) sample of non CSN cases (*N* = 44).

Results

Preliminary Analyses

Of the 1,020 male children included in the present study, 178 children completed the ChYMH-DD, and 842 children completed the ChYMH. Children who completed the ChYMH-DD were more likely to be referred for CSN funding than children who completed the ChYMH, χ^2 (1) = 55.35, $p < .001$. Specifically, 18 out of 178 children who completed the ChYMH-DD were referred for CSN funding, compared to 26 out of 842 children who completed the ChYMH (see Table 1). Additionally, children who completed the ChYMH-DD were more likely to have physical/medical illnesses $\chi2$ (1) = 12.999, $p < .001$, and experienced greater difficulties in activities of daily living than children who completed the ChYMH, $t(1017) = -19.980$, $p < .001$. It is also important to note that children who were assessed using the ChYMH-DD were less likely to have mental illness co-morbidity than children who completed the ChYMH $\chi2$ (1) = 9.323 $p < .01$, although both groups did not differ with respect to challenges in family functioning.

In total, 44 children and youth (4.31%) were referred by community agencies across Southwestern Ontario to be considered for CSN funding, whereas 976 (95.69%) were not referred for CSN funding. Of the 976 participants not referred for funding, 798 (82%) presented with no physical/medical health illnesses and 177 (18%) presented with 1 or more illness; in contrast, 32 (73%) of the CSN group presented with no physical/medical health illnesses and 12 (27%) presented with 1 or more. With respect to mental illness comorbidity, 451 (46%) of the non CSN group presented with 0 or 1 mental health illnesses and 525 (54%) presented with 2 or more. In addition, 22 (50%) of the CSN group presented with 0 or 1 mental health illnesses and 22 (50%) presented with 2 or more.

Primary Analyses

Results indicated that the full model provided a significantly better fit relative to the constant only model ($\chi^2 = 28.931$, $p < .01$, $df = 4$; See Table 2) suggesting that the predictors (i.e., risk factors) reliability distinguished participants referred for CSN funding to those not referred for funding. Results indicated that of the 4 predictors, impairments in family functioning and challenges with ADL significantly predicted CSN funding referral.[1] These results were consistent with the matched sample ($\chi^2 = 26.632$, $p < .01$, $df = 4$; See Table 3). See Tables 2 and 3 for regression coefficients, Wald statistics, odds ratios and 95% confidence intervals for the reported odds ratios. The predictor that most increased risk for complex special need funding referral was impairment in family functioning.

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[1] The pattern of results for the binary logistic regression analysis was consistent, regardless of whether ADL was treated as a continuous variable, or a categorical variable (e.g., mean split).

Table 1. Demographics of CSN Funding and Non CSN Funding Group

	N (%)		ChYMH Instrument (%)		ChYMH-DD Instrument (%)		Age in Years Mean (±S.D.)	
Non CSN	976	(95.69%)	824	(84.4)	152	(15.6)	10.88	(3.43)
Referred CSN	44	(4.31%)	18	(40.9)	26	(59.1)	12.86	(2.82)
Matched non CSN sample	44	(4.31%)	18	(40.9)	26	(59.1)	12.84	(2.78)
Total	1,020	(100%)	842	(82.5)	178	(17.5)	10.97	(3.43)

Table 2. Logistic Regression Results for Complex Special Needs Funding and Risk Factors (full sample)

Predictor	B	Wald	p Value	Odds Ratio (ExpB)	95% Confidence Interval
Challenges with activities of daily living	0.061	12.509	.000	1.063	[1.028–1.100]
Presence of physical/medical illness	0.308	0.713	.398	1.360	[0.666–2.777]
Comorbid mental illness	-0.339	1.110	.292	0.713	[0.380–1.338]
Impairments in family functioning	1.825	8.927	.003	6.206	[1.827–20.551]

Note: B = coefficient estimate of predictor; Wald = Wald Coefficient, indicates whether the B coefficient significantly differs from zero; p *Value = significance value, scores less than 0.05 are significant; Odds Ratio (Exponent B [ExpB]) = provides an estimate of the change in odds of being referred for complex special needs funding depending on change in the risk factor. Scores greater than 1 indicate that the predictor is associated with increased odds of being referred for complex special needs funding. Confidence interval = 95% confidence interval around the Odds Ratio.*

Table 3. Logistic Regression Results for Complex Special Needs Funding and Risk Factors (matched sample)

Predictor	B	Wald	p Value	Odds Ratio (ExpB)	95% Confidence Interval
Challenges with activities of daily living	0.106	5.471	.019	1.112	[1.017–1.215]
Presence of physical/medical illness	0.400	0.410	.522	1.491	[0.439–5.068]
Comorbid mental illness	-0.582	1.257	.262	0.559	[0.202–1.546]
Impairments in family functioning	2.416	11.118	.001	11.203	[2.707–46.359]

Note: See note under Table 2 describing table headings.

Discussion

Although children with CSN have significant clinical care costs (Stewart et al., 2017; Stewart & Hirdes, 2015), research to understand which children are referred for additional financial supports in the province of Ontario is lacking. The purpose of this study was to identify the combination of risk factors that could distinguish families referred for complex special needs funding from those who were not referred for CSN funding from mental health agencies in Southwestern Ontario. It was found that children identified as at risk for having a developmental disability, were more likely to be referred for CSN funding as compared to children who were not identified as at risk for a developmental disability. These findings are consistent with previous research, which suggests that children who present with intellectual and developmental delays, may have greater service needs than children without such delays (Coller et al., 2015). When we examined the specific risk factors assessed that could best differentiate children, as predicted, it was found that difficulties in completing activities of daily living and impairments in family functioning predicted funding referral; however, contrary to expectations, the presence of a physical/medical condition and mental illness comorbidity were not predictive of CSN funding referral in the present sample. These findings underscore both the role of impairments in ADL and family functioning as significant risk factors related to CSN funding referrals, and can serve to inform policy decisions around resource allocation.

Families seeking CSN funding in Southwestern Ontario were more likely to have impairments in family relationships (e.g., exhibit hostility toward the child, express feelings of being overwhelmed by the child's condition), and to a lesser extent, were more likely to have children who had challenges completing ADL independently. It is possible that deficits in adaptive functioning amongst children with CSN may lead to family members experiencing increased pressure to be available for their child on a daily basis (Contact a Family, 2011; Kilic, Gencdogan, Bag, & Arıcan, 2013; Teare, 2008). Indeed, the demands placed on the family of a child with CSN may result in high levels of physical and psychological stress, as well as financial burden. On the other hand, if parents present with health conditions (e.g., mental health, disabilities, and substance use issues), they may be less likely to be available to address their child's needs, feel competent in caring for their child, familiarize themselves with resources that may be of assistance to the child, participate in their child's treatment and may experience greater degrees of perceived burden (Angold et al., 1998; Head & Abbeduto, 2007; Preyde, Cameron, Frensch, & Adams, 2011; Stewart et al., 2017). This can further limit the opportunities the child is provided with to develop skills that may help him/her become more independent with respect to daily living.

Contradictory to previous research which has suggested that the multiplicity of physical and mental health issues is the main characteristic that distinguishes CSN children (Burnside, 2012; Hewitt-Taylor, 2005), the present study found that physical/medical illness and mental health comorbidity were not significantly predictive of CSN funding referral. The lack of significant differences may have several explanations. First, studies examining children with complex needs have found that although these children are at a much higher risk for comorbid psychopathology, diagnoses of psychopathology prove challenging due to a variety of reasons (e.g., differential presentation of symptomology; dependence on parental report for symptoms, and diagnostic overshadowing; Cooper, Melville, & Einfeld, 2003; Costello & Bouras, 2006; Matson & Matson, 2015; Meltzer, Gatword, Goodman, & Ford, 2000). Alternatively, it is possible that mental health comorbidity was not a distinguishing factor of the CSN group because the current sample was a highly clinical one (i.e., both groups seeking mental health services), with high rates of mental health comorbidity in both groups. Another interpretation is that the predictors used were not specific enough to ascertain degree of medical and psychological severity. For example, some physical illness diagnoses may be more severe than others; due to the limited sample size, however, we could not explore variability in diagnosis (e.g., perhaps only severe health impairments differentiate CSN youth from non-CSN youth in clinically referred samples). Future research involving larger samples of youth referred for CSN could address this limitation. Importantly, given our use of a multivariate model in the present study, utilizing more precise measures of psychiatric disorder comorbidity and medical/physical illnesses, could also impact the relative strength of other predictors in the model (i.e., activities of daily living and family functioning).

Limitations

The findings of this study need to be taken into account within the context of its limitations. First, it is important to note that due to the cross-sectional nature of the study, the study does not provide information with respect to the direction of the relationship between impairments in family functioning and challenges in completing ADL and how these impact families need for funding. The findings do, however, indicate the combination of risk factors (i.e., impairments in family functioning and challenges in completing ADL) that profile children who are at the greatest risk for additional financial support. Second, we were only able to examine risk factors among males referred for CSN funding; future research should also examine whether males and females applying for CSN funding present with different risk factors. Third, as previously stated, the sample consisted of a sample of children seeking mental health services in Southwestern Ontario, which limits the generalizability of the study, as this sample may not be representative of the broader population of children with CSN who may seek funding at different agencies across Ontario and elsewhere (e.g., children's hospitals or treatment centres). Finally, the small sample size of children referred for CSN funding limited the number of risk factors that could be examined in the present study. For example, research suggests that aggression to self and others may be important markers of service referral among clinical samples (Pompili et al., 2012; Tremmery et al., 2014). Nevertheless, our findings provide the first empirical investigation of factors related to CSN funding referral in Southwestern Ontario, and future large-scale studies could examine additional factors that may be associated with funding referral (e.g., socio-demographic status, location of family in relation to location of services needed).

Conclusions and Implications

By examining children referred for funding for CSN, a combination of risk factors that distinguished families seeking CSN funding from other clinically referred children were identified. Findings suggest that although many clinically referred children present with physical/medical and mental health problems, children and their families applying for complex special needs funding experience greater difficulties in family functioning, and to a lesser extent, greater activities of daily living. These findings suggest that clinicians need to move away from assessments and treatment plans that only examine the child, and examine factors that extend beyond just the child's presentation (also see Bailey, Raspa, & Fox, 2012; Preyde et al., 2015). Additionally, assessments evaluating the impact that the child's adaptive functioning has on the family (or vise versa), should also be considered. The results of the present study underscore the need for utilizing comprehensive assessments (e.g., ChYMH and ChYMH-DD) that take into account the families functioning and ability to attend to their child's needs, when making decisions around funding allocation for children with CSN.

Key Messages From This Article

Professionals. To promote best outcomes for children with complex special needs, it is important to conduct a thorough assessment and create treatment plans that consider the family. Special attention needs to be paid to family functioning and impairments the child has with completing daily living tasks (e.g., eating, dressing, personal hygiene), as these factors have known to be present among families requiring extensive resources.

Policymakers. In order to make informed decisions about funding allocation for children with complex special needs, it is essential to conduct thorough assessments to get a comprehensive understanding of each child and family.

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Investigating Imagination in Adults With Autism Spectrum Disorder With Art-Based Assessments

Authors

Olena Helen Darewych,[1]
Nicky J. Newton,[2]
Kevin Wayne Farrugie[3]

[1] Department of Spiritual Care and Psychotherapy, Waterloo Lutheran Seminary, Wilfrid Laurier University, Waterloo ON

[2] Department of Psychology, Wilfrid Laurier University, Waterloo ON

[3] Woodview Mental Health and Autism Services, Brantford ON

Correspondence

odarewych@wlu.ca

Keywords

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Abstract

This mixed-methods convergent study examined whether the Scribble Drawing, Bridge Drawing with Path (BDP), and Future Trip Drawing art-based assessments from the field of art therapy, could be utilized as creative methods in evaluating imagination and symbolic development of drawings in adults with autism spectrum disorder (ASD). Fourteen (N = 14) adults with medium- to high-functioning ASD (M_{age} = 27.7 years) participated in a single individual study session during which they completed the three aforementioned imaginative drawings. The results showed that the three art-based assessments with supporting written and verbal narrative associations can be considered as effective creative methods to measure imagination and symbolic development in adults with ASD. Most of the participants envisioned, developed, and described more non-social symbols representing real places and objects from their world than social (self and people) symbols in their Scribble Drawing (79%; n = 11) and Future Trip Drawing (86%; n = 12). One compelling Scribble Drawing finding was that half of the participants' scribble lines directly embodied symbols not present to their senses; as a result, there was no need for them to add to their scribble lines to create their concrete symbols. This finding supports previous literature that certain individuals with ASD have detail-focused cognitive processing and drawing styles. A noteworthy BDP finding was that participants' BDP end points led to things that made their life feel meaningful (i.e., art program, nature, theatre). This finding calls upon developmental service providers to implement recreation programs and organize excursions to local art galleries and museums for adults with ASD. The authors believe that the results of this study will inspire future art-based assessment research investigating imagination, symbolic development, and executive function abilities in adults with ASD.

Imagination is a complex cognitive construct that involves an individual's ability to create mental images of people, places, and objects that are not present to their senses (Chodorow, 1997). Our mental images are based on our past memory (episodic memory), current life experiences, and future visions also known as episodic foresight (EpF; Suddendorf & Moore, 2011). Individuals with autism spectrum disorder (ASD) tend to display signs of impairment in communication, social engagement, and imagination (American Psychiatric Association, 2013; Wing, Gould, & Gillberg, 2011). Some individuals with ASD also exhibit difficulties with executive function (EF): completing tasks in a timely manner, remembering the sequence of a multi-step activity, and transitioning from one activity to another (Hill, 2004). Since symbols in drawings are the visible external products of one's internal mental images (Kast, 1990/1992; Pelaprat & Cole, 2011), a number of studies have used the impossible-person drawing task (Karmiloff-Smith, 1990), with or without adaptations to measure imagination in children with ASD (e.g., Hollis & Low, 2005; Leevers & Harris, 1998). The Karmiloff-Smith's impossible-person drawing task first presents participants with a picture of people walking towards a magic door which opens to a path leading to a planet in space. Participants are informed that when the people walk through the door they change into funny and strange looking people which they have not seen before. Participants are then directed to draw pictures of the changed people after they have walked through the magic door. Early impossible person drawing studies supported the idea that children with ASD have deficits in drawing imaginative symbolic content (Craig, Baron-Cohen, & Scott, 2001; Low, Goddard, & Melser, 2009; Scott & Baron-Cohen, 1996). However, recent impossible person drawing studies have concluded that the social aspect (i.e., draw people) of the drawing directive restricts participants with ASD to express their imagination (Allen & Craig, 2016; Ten Eycke & Müller, 2015). A number of researchers have underscored that the social impairment of children with ASD affects their drawings of symbols of people and social scenes (Celani, 2002; Jolley, O'Kelly, Barlow, & Jarrold, 2013). Furthermore, due to executive function planning deficits, they tend to depict familiar and local symbols from their real world rather than fantasy or unreal symbols in their drawings (Leevers & Harris, 1998; Scott, 2013). Other drawing task studies have also concluded that individuals with ASD have a tendency to generate detail-focused drawings (Booth, Charlton, Hughes, & Happé, 2003; Happé & Frith, 2006).

To date, the vast majority of imaginative drawing studies in the literature have been conducted with children with ASD. Since imagination expands the entire developmental lifespan of individuals and not only childhood, there is a need for further drawing studies investigating imagination in adults with ASD.

Materials and Methods

The purpose of this mixed-methods convergent study with an interrater agreement and art-based element was to better understand the imaginative and symbolic formation abilities of adults with ASD, and to determine if the Scribble Drawing (Cane, 1951), Bridge Drawing with Path (BDP; Darewych, 2013), and Future Trip Drawing (Liebmann, 1986) art-based assessments from the field of art therapy, could be used as creative methods to measure imagination and symbolic development in adults with ASD. All three art-based assessments, also known as projective drawings, have the potential to indirectly tap into an individual's imaginative cognitive and drawing abilities. The research questions for this study were:

1. Will adults with ASD depict and describe symbols in their drawings not present to their senses?
2. Will adults with ASD generate more non-social (places and objects) than social (self and people) symbols in their drawings?

Convenience sampling was used in this study and participants were recruited from an Autism Centre located in Southern Ontario. Soft and hard copies of the recruitment flyer and informed consent were distributed to potential participants by the Autism Centre to its membership and partnering agencies. Fourteen adults (11 male, three female) with a chronological age range of 21 to 34 (M_{age} = 27.7 years, SD = 4.50) and a formal diagnosis of medium- to high- functioning autism with verbal and/or written expressive communication skills volunteered to participate in this study. Participants' self-identified their ethnic background as Canadian (57%; n = 8), Canadian-Dutch (14%; n = 2), Middle-Eastern (14%; n = 2), Italian (7%; n = 1), and Portuguese (7%; n = 1). At the time of the study, half of the participants (50%; n = 7) were enrolled in a community-based art program. All participants were right-handed and most of the participants (86%; n = 12) used digital devices at home as communication and leisure tools.

Prior to commencing the study, participants completed a consent form with the support of a family member or case worker which highlighted the purpose of the research, anticipated study benefits, potential emotional risks, and participants' ability to terminate study participation at any time. Participants also completed a demographic form requesting the following information: age, gender, ethnicity, handedness, and hobbies. Each participant attended a single one hour study session which was facilitated by a professional art therapist (third author). Eleven participants attended the study session independently whereas three participants chose to have their family member or support worker present to help with understanding the art directives. During the single study session, each participant was directed to complete the Scribble Drawing (Cane, 1951), Bridge Drawing with Path (BDP; Darewych, 2013), and Future Trip Drawing (Liebmann, 1986).

The Scribble Drawing (Cane, 1951) is a two-step, open-ended art-based assessment that directs an individual to create a spontaneous image out of a scribble. The drawing can be used to examine if an individual has the cognitive and drawing capacity to develop symbolic representations of people, places, or objects not present to their senses from their abstract scribble lines. The verbal instructions given to participants were: "With your eyes opened or closed, draw a scribble. When finished drawing your scribble, look at your scribble at different angles. Do you see anything in your scribble? Develop your scribble into something and provide a title for your image." The instructions were not given at once but step by step. A Scribble Drawing interval coding system developed for this study rated the following symbolic image content variables: symbol transformation and symbol type.

The Bridge Drawing with Path (BDP; Darewych, 2013) is a three-step, goal-oriented art-based assessment which guides an individual to imagine and draw a bridge which is connected to a path. It is theorized that the path depicted in the drawing symbolically represents the creator's past, present, or future life pathway which leads them to meaningful people, places or objects. The bridge and path can be perceived as local and global symbols. Participants were directed to "Draw a bridge from someplace to someplace. The bridge connects to a path. Draw the path and write or say where it leads you to. Provide a title for your image." The following five BDP symbolic image content variables were measured using the BDP interval coding system: bridge type, bridge connection, path quadrant, matter under bridge, and self-depiction. The BDP written and verbal narrative association results from this study were compared to the BDP normative sample database (Darewych, 2014).

The Future Trip Drawing (Liebmann, 1986) is a one-step art-based assessment that prompts an individual to imagine and draw an image of a trip they would like to take in the future. Participants were directed to "Imagine you are going on a trip next week. Where would you like to travel? With the materials provided, draw the place you would like to visit. Provide a title for your image." A Future Trip Drawing interval coding system developed for this study rated the following symbolic image content variables: symbol type and self-depiction.

Participants completed the BDP drawing with an HB No. 2 pencil on an off-white 8.5 in. × 11 in. paper but had a choice to complete the Scribble Drawing and Future Trip Drawing with traditional art materials (i.e., coloured markers, coloured pencils, crayons, HB No. 2 pencils, off white 8.5 in. x 11 in. paper) or on a password protected digital touchscreen laptop with the user-friendly Windows 8 FreshPaint art-making application. Creating digital images is suitable for high sensory sensitive adults with ASD who prefer using mess-free and texture-free art materials (Darewych, Carlton, & Farrugie, 2015).

Two independent raters who were professional art therapists, and blind to the study research questions, coded the de-identified drawings. The raters were trained to code symbolic image variables by the principle investigator (first author). Interrater agreement analysis using SPSS Cohen's Kappa (Landis & Koch, 1977) was used to determine consistency between the two image raters. For this study, a Kappa value of 0.6 or greater was adopted as a good level of agreement. The second author conducted the SPSS-Kappa analysis. The expert rater's (rater two) data was used for data analysis and the first two authors conducted a thematic analysis of the narratives which were elicited by participants' drawings. Participants' de-identified demographic information form, drawings, writings, verbal comments, and session progress notes were the raw research data. The study was approved by Wilfrid Laurier University's research ethics board.

Results

During the single one hour study session, participants were directed to complete the Scribble Drawing first. All participants created a Scribble Drawing and more than half (64%; *n* = 9) of participants chose to create their Scribble Drawing on the digital touchscreen device. Three-quarters (79%; *n* = 11) of the participants developed their abstract scribble lines into a visible non-social symbol. One participant depicted themselves in their Scribble Drawing. Half of the participants' (50%; *n* = 7) meandering scribble lines directly embodied symbols. Figure 1 depicts a digital scribble drawing created by Tim (pseudonym) whose meandering lines straightforwardly represented mountains. Based on a thematic analysis of the narratives associated with the Scribble Drawings, one major theme was identified: concrete symbols. Participants described concrete symbols such as nature (e.g., mountain, water) or objects (e.g., hearts, quilt, train, and square). Figure 2 illustrates Paul's (pseudonym) Scribble Drawing which he developed into a golf course. In examining the Scribble Drawing interrater agreement scores, relatively substantial agreement (*k* = .66) was obtained for symbol transformation and moderate agreement (*k* = .52) was obtained for symbol type.

Upon completion of the Scribble Drawing, participants were prompted to complete the BDP. Eighty-six percent (86%; *n* = 12) completed the BDP leading to a goal-oriented endpoint (e.g., art program, city, home). One participant decided not to complete a drawing and another participant chose to draw a person instead. The two participants with medium functioning ASD who did not complete the BDP may not have understood the multi-step BDP directive or may not have grasped the bridge and path symbols. More than half (64%; *n* = 9) of participants depicted a simple bridge symbol or a path symbol in their BDP but not both. Three participants (21%; *n* = 3) depicted themselves in their BDP. Image raters struggled with coding BDP symbolic variables into the themes of bridge connection (*k* = .20), bridge type (*k* = .36), path quadrant (*k* = .17) and matter under bridge (*k* = .32), due to uncertainty about whether the simple symbol depiction was a bridge or a path. Relatively substantial agreement (*k* = .64) was obtained for axis of paper and perfect agreement (*k* = 1.0) was obtained for self-depiction. The two most common BDP narrative themes generated by participants were: local bridges and famous bridges. Figure 3 shows Kristina's (pseudonym) BDP depicting a local park bridge leading to a waterfall whereas Figure 4 portrays Daniel's (pseudonym) BDP illustrating the famous Niagara Falls Rainbow Bridge.

Figure 1. Scribble drawing with mountains

The third and final drawing was the Future Trip Drawing. One participant was not comfortable with travelling or flying outside of his city therefore; the directive was modified for them from "Where would you travel" to "Where would you go" which prompted the participant to draw a local theatre. Only one participant did not complete a Future Trip Drawing, choosing to draw a square shape instead. Three-quarters (79%; n = 11) of participants decided to create their

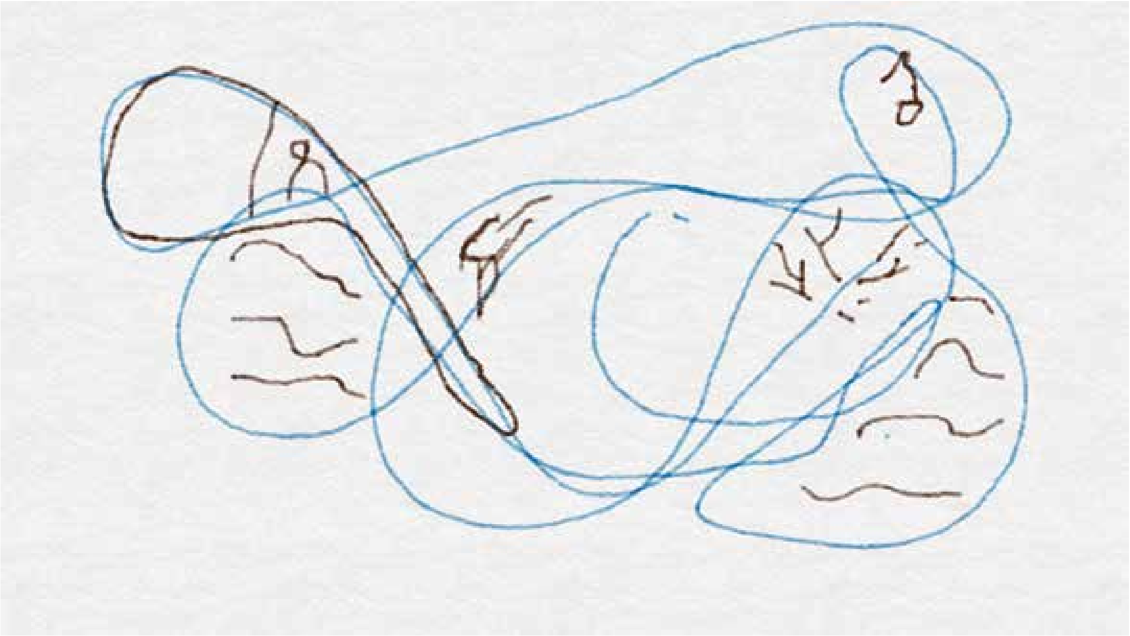

Figure 2. Scribble drawing with golf course

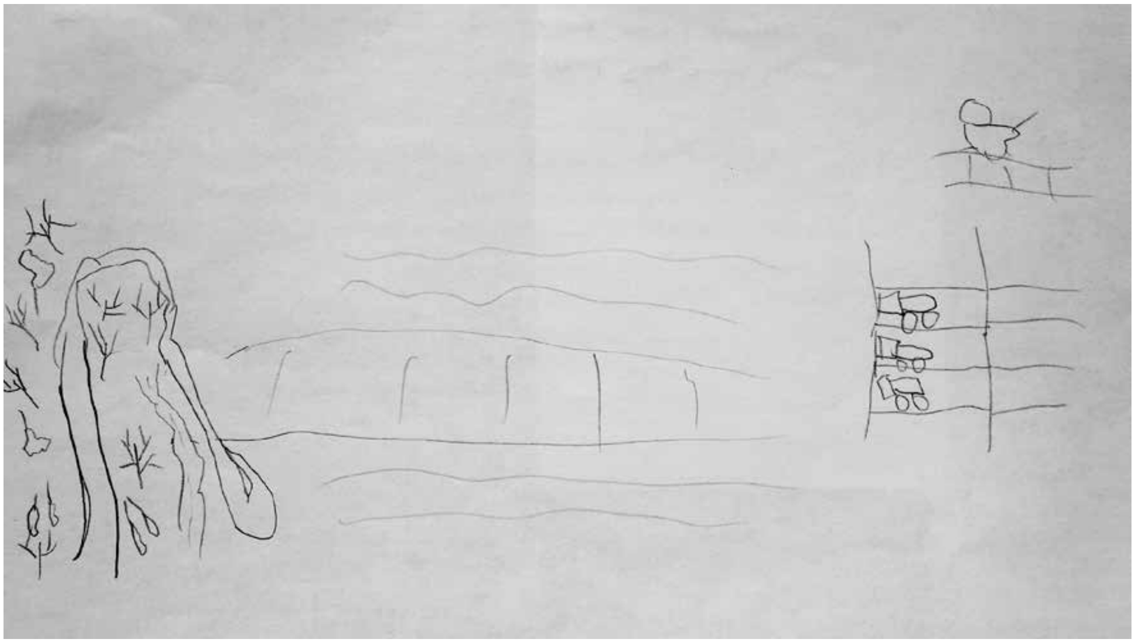

Figure 3. Bridge drawing to waterfall

Future Trip Drawing on the digital touchscreen device. The majority of participants (79%; *n* = 11) depicted non-social symbols in their Future Trip Drawing. Two participants (*n* = 2) depicted themselves and non-social symbols in their Future Trip Drawing. The two most common Future Trip narrative themes generated by participants were: vacation destinations and community programs. Andrew (pseudonym) created a digital Future Trip Drawing to a Cuban beach resort (see

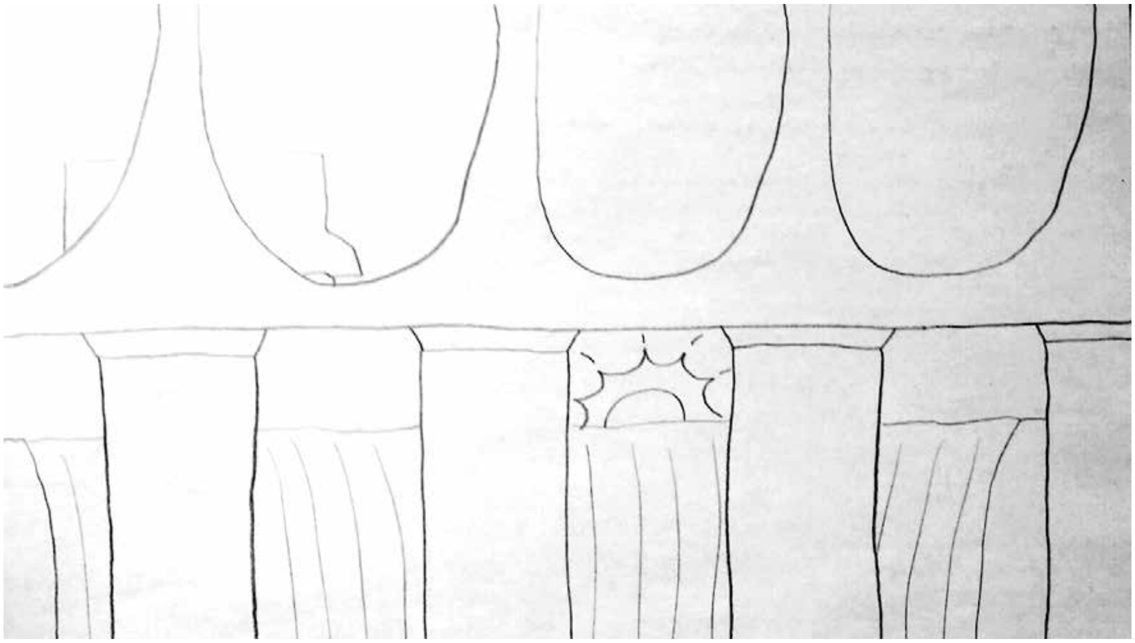

Figure 4. Niagara Rainbow Bridge

Figure 5. Future trip drawing to Cuban resort

Figure 5) while Luke (pseudonym) drew a future trip with pencil and paper to his favourite community indoor bowling alley. In examining the Future Trip Drawing interrater agreement scores, moderate agreement (*k* = .63) was obtained for symbol type and substantial agreement (*k* = .76) was obtained for self-depiction.

The complete image variable results for the three drawings are presented in Table 1 whereas the Kappa results of the interrater analysis for the three drawings are displayed in Table 2.

Table 1. Drawing Variables

Drawing Variables	*N = 14* 79% M Age 21–34
Scribble drawing	
Scribble completion	100%
Non-social symbols	79%
Self symbols	7%
Direct embodied symbols	50%
Digital media preference	64%
Bridge drawing with path (BDP)	
BDP completion	86%
Bridge or Path symbol	64%
Self symbol	21%
Future trip drawing	
Future trip completion	93%
Non-social symbols	79%
Non-social and self symbols	14%
Digital media preference	79%

Table 2. Interrater Kappa Agreement for Drawings

Drawing Variables	*Raters Average*	*Kappa Agreement**
Scribble drawing		
Symbol transformation	.66	Substantial agreement
Symbol type	.52	Moderate agreement
Bridge drawing with path (BDP)		
Axis of paper	.64	Substantial agreement
Bridge connection	.2	Slight agreement
Bridge type	.36	Fair agreement
Path quadrant	.17	Slight agreement
Matter under bridge	.32	Fair agreement
Self depiction	1	Perfect agreement
Future trip drawing		
Symbol type	.63	Moderate agreement
Self depiction	.76	Substantial agreement

** Landis and Koch (1977).*

Discussion

The first research question for this study was: Will adults with ASD depict and describe symbols in their drawings not present to their senses? Most participants imagined and depicted symbols in their three drawings not present to their senses and described the symbolic meaning verbally or in writing. One compelling Scribble Drawing finding was that half of the participants' scribble lines directly embodied symbols not present to their senses; as a result, there was no need for them to add or fill in their scribble to create their concrete symbol (see Figure 1). Perhaps this straightforward representation of symbols is due to individuals with ASD having detail-focused cognitive processing and drawing styles (Booth, et al., 2003; Happé & Frith, 2006). Since the concrete symbols were not explicitly visible to the raters until they read the narrative associated with each Scribble Drawing, it is important that researchers and clinicians specifically request individuals with ASD to express the symbolic content of their drawings verbally or in writing.

The second research question was: Will adults with ASD generate more non-social (places and objects) than social (self and people) symbols in their drawings? Participants in this study generated more concrete non-social symbols representing real places and objects from their world than social symbols in their drawings. This finding supports the idea that certain adults with ASD have unique imaginative, cognitive, and drawing abilities, and that their imagination may be restricted when drawing tasks include social content (Allen & Craig, 2016; Ten Eycke & Müller, 2015). Furthermore, this finding supports Celani's (2002), Jolley et al.'s (2013), and Ten Eycke's and Müller's (2015) notion that social deficits in individuals with ASD extend to their imaginative drawings.

One interesting BDP finding was that more than half of participants depicted a bridge symbol or a path symbol, but not both. These results validate the notion that some individuals with ASD have challenges with executive function, particularly with organizing and remembering steps in a multi-step task (Hill, 2004). The multi-step BDP results emphasize the importance for clinicians to design clinical treatment plans that take into account the maintenance and development of executive function in adults with ASD. Another noteworthy BDP finding was that similar to previous BDP studies (Darewych, 2013; Darewych, 2014), participants' BDP end points led to things that made their life feel meaningful (i.e., art program, city, home, local theatre, nature). This finding calls upon service providers to implement recreation programs and organize excursions to local art galleries and museums for adults with ASD which enhance their well-being and inclusion in society.

Overall, the drawing task results of this study are suggestive that the Scribble Drawing (Cane, 1951), Bridge Drawing with Path (BDP; Darewych, 2013), and Future Trip Drawing (Liebmann, 1986) art-based assessments from the field of art therapy can be considered as effective creative methods to measure imagination and symbolic development in adults with medium- to high-functioning ASD with verbal and/or written expressive communication abilities. The two-step, open-ended Scribble Drawing can provide information about an individual's ability to imagine and then draw concrete symbols within abstract meandering lines. The three-step BDP can explicitly be used in therapy to assess, maintain, and develop imagination and executive function in adults with ASD. The one-step Future Trip Drawing in the research and clinical realm can provide greater understanding of imagination and episodic foresight in adults with ASD. Imagining and drawing the future allows individuals with ASD to cognitively prepare themselves for upcoming events (Suddendorf & Corballis, 2007). There is some evidence now that adults with ASD exhibit deficits in episodic foresight (Crane, Lind, & Bowler, 2013; Lind & Bowler, 2010). Since one-time drawings simply provide snapshot presentations of participants' imaginative thinking and symbolic abilities, future studies administering a series of the three drawings over time would increase the reliability of the art-based assessments as measures of imaginative and symbolic content. One striking art form finding was that most participants chose to create their Scribble Drawing and Future Trip Drawing on the digital device with the user-friendly FreshPaint art-making application rather than with the traditional materials. This finding justifies Darewych et al.'s (2015) call for further studies in our current digital age that examine this technology as a new creative media in clinical settings.

The limitations of the present study include a relatively small sample size (N = 14) and no control group. In future research, the use of larger samples of adults with ASD and neurotypical (adults without ASD) comparison groups is recommended in order to provide more robust findings. A third limitation was that the art-based directives were only administered verbally. The administration of the art-based directives in multiple ways – verbally, and in written script, may have helped participants fully understand the drawing instructions. Despite the methodological limitations, the present study is the first to explore imagination in adults with ASD utilizing the three open-ended and non-social content arts-based assessments from the field of art therapy**.** The authors invite researchers to replicate and extend this study with children and adolescents with medium- to high- functioning ASD.

Key Messages From This Article

Persons with disabilities. You have unique creative talents and visual imaginative abilities.

Professionals. Implement arts programs for individuals with autism and other developmental disabilities to maintain their active imagination and further develop their creative and executive function faculties.

Policymakers. Continue advocating and financially supporting arts and other social inclusion programs for adults with ASD that make their life feel meaningful.

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Exploratory, Pilot Study: Treatments Accessed by Caregivers of Children with Down Syndrome – An Internet Survey

Authors

Nicole Neil,[1]
Theresa Fiani,[2]
Arlene Mannion,[3]
Meagan Lynch[3]

[1] Faculty of Education,
Western University,
London ON

[2] Department of
Psychology,
The Graduate Center,
City University of New
York,
New York NY

[3] School of Psychology,
National University of
Ireland,
Galway IE

Correspondence

nneil@uwo.ca

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Abstract

Down syndrome is associated with a range of developmental strengths and challenges. The treatment use of individuals with Down syndrome along with associated factors have not yet been determined. In a pilot study to address this issue, we elected to conduct an online survey rather than a classical representative population survey to generate relevant information quickly. An online survey was completed by 162 primary caregivers of children and youth with Down syndrome. Caregivers reported the types of treatments children were currently receiving and had received in the past, along with the overall satisfaction with treatments. Associations with other child variables (e.g., age, gender, and race) and family characteristics were also examined. Findings indicate that children were currently receiving a mean of 6.1 (SD = 3.5) different types of therapy treatments; the most common treatments was speech–language therapy currently received by 73%. Only 2.4% of children were currently receiving applied behaviour analytic treatment, an empirically supported therapy. Caregivers reported using a number of treatments without empirical support including facilitated communication, holding therapy, and auditory/sensory integration. Caregivers tended to agree that each treatment was efficacious and contributed to their child's growth. Treatments that were associated with strong agreement included medication (69.8%), care from family and friends (62.8%), assistive technology (58.3%), and floortime (55.6%). Future research should focus on understanding the process of treatment selection by caregivers of children with Down syndrome and develop accessible guidelines on empirically supported therapies.

Down syndrome (DS), one of the most common chromosomal abnormalities, is associated with physical co-morbidities such as heart defects and reduced immunological function (Kent, Evans, Paul, & Sharp, 1999) and a characteristic behavioural phenotype including weaknesses in communication (e.g., expressive language), cognition (e.g., verbal short-term memory), and motor (e.g., low muscle tone) domains (Fidler, 2005), which warrant intervention.

The varied physical, intellectual and behavioural challenges associated with DS necessitate a variety of individualized treatments. Caregivers of children with disabilities regularly report a dearth of information, making treatment selection difficult (Hummelinck & Pollock, 2006; Nordfeldt, Ängarne-Lindberg, Nordwall, & Krevers, 2013), exacerbated by negative attitudes and low expectations among treatment providers (Prussing, Sobo, Walker, & Kurtin, 2005). Thus, they independently seek information (often from a vast array on the internet) to advocate for their child's best interests (Alsem et al., 2017; Prussing et al., 2005). This task can quickly become overwhelming and may lead to pursuit of treatments not known to have any beneficial effects or that might even be iatrogenic.

Extant treatment literature empirically supports the efficacy of some treatments (Lemons, Powell, King, & Davidson 2015; Millar, Light, & Schlosser, 2016; Neil & Jones, 2016) including applied behaviour analysis (Neil & Jones, 2016) and reading and phonological awareness treatments (Burgoyne et al., 2012), which target a range of weaknesses including communication (Bauer & Jones, 2015; Feeley, Jones, Blackburn, & Bauer, 2011; Jones, Feeley, & Blackburn, 2010), reading (Burgoyne et al., 2012; Naess, Melby-Lervag, Hulme, & Lyster, 2012), phonological awareness (Burgoyne et al., 2012), and mathematics (Lemons et al., 2015). Unfortunately, treatments established as ineffective for DS continue to be provided. Some of these treatments are considered controversial (Nickel, 1996) and are not recommended because of ineffectiveness or potential harm for individuals with developmental disabilities (Mercer, 2001; Mostert, 2001). These include facilitated communication, where communication is mediated via pointing and typing by a "facilitator," and holding therapy, consisting of forced holding by a therapist for a fixed period of time or until resistance stops. Others, such as sensory/auditory integration training lack support for individuals with DS (Baranek, 2002; Dawson & Watling, 2000; Lang et al., 2012). In this treatment, individuals are repeatedly and systematically exposed to sensory stimulation.

To provide guidance for treatment professionals, facilitate evidence-based practice, and encourage research into under-examined treatments, we sought to better understand: (1) the number and types of treatments utilized by caregivers of children with DS; (2) how child characteristics influence the number of treatments used; and (3) how caregivers rate treatment efficacy. An Internet survey was used to answer these questions. In certain situations, this method of online data collection can provide valuable information for research (Gosling, Vazire, Srivastava, & John, 2004; Preckel & Thiemann, 2003) and is a frequently used tool in behavioural research (Granello & Wheaton, 2004).

Materials and Methods

Participants

Participants included 162 primary caregivers of children with DS in their household. Socio-demographic information was collected for primary and secondary caregivers and for children with DS. Survey information was provided by the primary caregivers. Of children whose gender was reported (*n* = 138), the average age was 7.35 years (*SD* = 4.95, range = 0–17); 53.6% (*n* = 74) were boys and 46.4% (*n* = 64) were girls. Families most commonly reported white racial/ethnic backgrounds (92.8%, *n* = 128), whereas 7.2% were families of colour (e.g., Black, Asian/Pacific Islander). For detailed socio-demographic breakdown including the primary caregiver, secondary caregiver, and child characteristics, refer to Table 1 on page 42. Participants presented with a wide range of co-morbid diagnoses including attention-deficit/hyperactivity disorder, autism spectrum disorder (ASD), and cystic fibrosis; refer to Table 2 on page 44 for more details.

Materials

The first and third authors developed the questionnaire (available on request) based on existing literature investigating caregiver treatment use among individuals with other developmental disabilities (Green et al., 2006; Goin-Kochel, Mackintosh, & Myers, 2009; Hume, Bellini, & Pratt, 2005; Martin et al., 2013). Twenty-five questions assessed demographic characteristics of primary and secondary caregivers and the child with DS (e.g., country of residence, age, gender, race/ethnicity, education, marital status). Caregivers selected from a list of 35 treatments those which their child/family was receiving/had received, and rated each treatment's effectiveness by indicating their agreement with the following statement: "This treatment was effective and contributed to my child's growth" on a five-point Likert scale (1 = strongly disagree). The generic "growth" term was used so that families could apply the statement to multiple types of treatment. However, the ratings do not tell us what specific behaviors primary caregivers saw as changed due to a given treatment/therapy, though the caregivers might have had a specific behaviour or behaviours in mind when they responded. For example, caregivers were most likely indicating growth in language and communication as a result of speech therapy.

Procedures

The web-based survey was distributed via chapters of the Global DS Foundations [http://www.globaldownsyndrome.org], and via colleagues, who then distributed it to caregivers of children with DS. The survey was live from June 2016 to January 2017. Participants accessed the questionnaire after providing informed consent, and all submitted responses were stored on a secure, university-controlled server. Participation was confidential, as no identifying information as collected. Participants did not receive compensation. Statistical analyses were interpreted at the 95% confidence level. The study protocol was reviewed and approved by the Institutional Review Board at Michigan State University.

Results

Treatments

Note: Percentages were based upon 162 submitted surveys. In families with more than one child with Down syndrome, the average number of particular treatments per child was used in the analysis. In some cases a primary caregiver did not indicate (a) current, (b) past, or (c) never for a particular treatment. Such omissions were classified as missing data. As a result of missing data, the sample sizes varied across treatment. Zeros represent no primary caregivers reporting use of that treatment.

Treatment Use. At least one primary caregiver endorsed each of the 35 treatments listed in the survey (see Table 3 on page 45 for rank order of treatments used). The most common treatment, speech therapy, was presently used by 73% of caregivers and previously used by 19%. The next most commonly currently used treatments were care from family or friends, occupational therapy, and physical therapy. On average, caregivers reported currently using six treatments (*M* = 6.1, *SD* = 3.5, range = 0–20), higher than mean past treatments (*M* = 5.1, *SD* = 4.3, range 0–23).

A three-way analysis of variance tested the effects of age, gender, and race on number of current treatments. As shown in Table 4 on page 46, main effects of age and race were not statistically significant, however, girls (*M* = .85, *SD* = .06) received significantly more treatments than boys (*M* = .69, *SD* = .05), *F* (1, 133) = 5.25, *p* = .02, η^2 = .04. Figure 1 depicts current treatments by gender. As depicted in Figure 2 on the following page, there was a significant interaction between age group and race, *F* (2, 133) = 5.23, *p* = .007, η^2 = .08. For 0–6 year olds, white caregivers (*M* = .80, *SD* = .03) reported significantly more current treatments than caregivers of colour (*M* = .62, *SD* = .08), *p* = .046. In 7–12 year olds, caregivers of colour (*M* = .91, *SD* = .10) reported significantly more current treatments than white caregivers (*M* = .69, *SD* = .05), *p* = .05. There were no significant differences in current treatments between white caregivers (*M* = .66, *SD* = .05) and caregivers of colour (*M* = .93, *SD* = .15) for the age group of 13–18 years old. In white caregivers, 0–6 year olds received significantly more interventions than 13–18 year olds (*p* = .030). In caregivers of colour, 0–6 year olds received significantly more interventions than 7–12 years old (*p* = .030).

Caregiving Ratings of Treatment Efficacy. Figure 3 on page 41 shows caregiver ratings of the efficacy of treatments and contribution

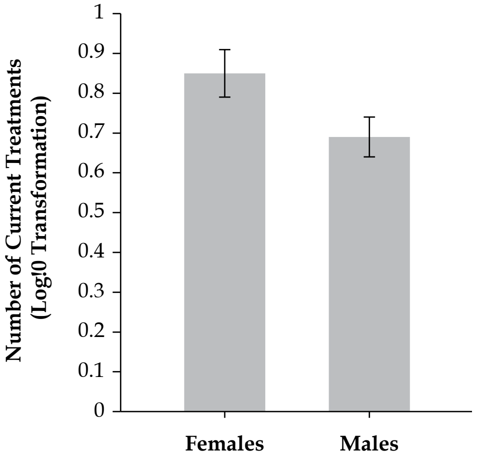

Figure 1. Number of caregiver reported treatments currently being used by gender. Error bars represent the standard error of the mean.

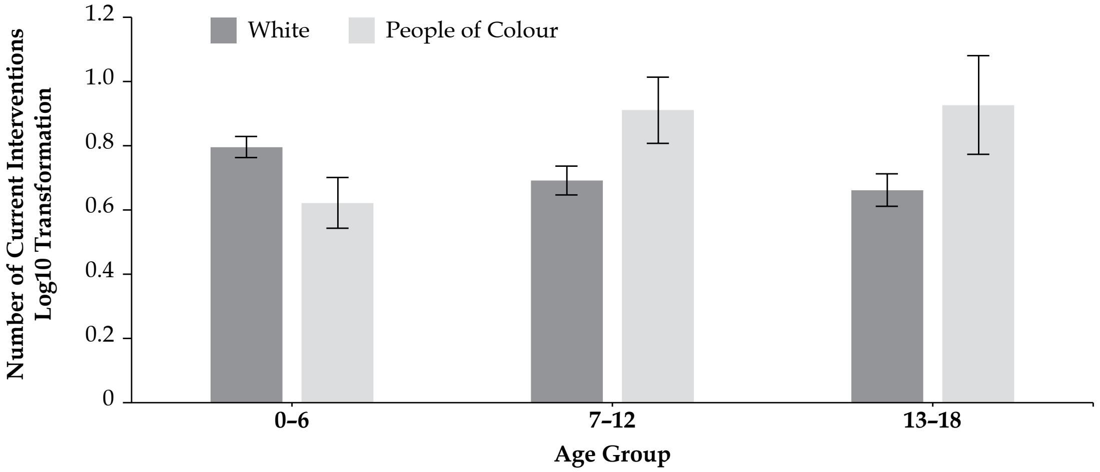

Figure 2. Number of primary caregiver reported treatments currently being used by age group and race. Error bars represent the standard error of the mean.

to their child's growth. Most family members agreed that each treatment was efficacious and contributed to growth. Caregivers strongly supported medication (69.8%), care from family and friends (62.8%), assistive technology (58.3%), and floortime (55.6%) as effective contributors to their child's development. Caregivers also strongly supported holding therapy (100%) though this was used only by three families. The rates of strong disagreement for effectiveness of specific therapies were much lower than for the rates of strong agreement. The highest rate of caregivers (6.3%) strongly disagreed that family counselling significantly impacted their child's growth. Adaptive physical education and social skills training also had higher dissatisfaction rates (5.3% and 5.0% strongly disagreed, respectively).

Discussion

This study sought to better understand: (1) the number and types of treatments utilized by caregivers of children with DS; (2) how child characteristics influence the number of treatments used; and (3) how caregivers rate treatment efficacy. Some treatments accessed by families were empirically supported, while others were not. The most commonly used treatment was speech therapy, consistent with communication problems as characteristic among individuals with DS (Fidler, 2005). Fortunately, speech therapy is empirically validated (Kumin, 1999; Rondal & Buckley, 2003) for DS. Least common treatments included applied behaviour analysis, despite extensive empirical support for the use of applied behaviour analysis for individuals with DS (for systematic review, see Neil & Jones, 2016). Several reported current and past treatments are not evidence-based for use with children with DS. Almost 10% of the participants reported current use of facilitated communication, despite extensive data against its effectiveness (Bligh & Kupperman, 1993; Cabay, 1994; Eberlin, McConnachie, Ibel, & Volpe, 1993; Tostanoski, Lang, Raulston, Carnett, & Davis, 2014). Additional treatments which persisted despite lack of evidence-base included craniosacral/myofascial (Ernst, 2012; Hartman, 2006), auditory and sensory integration (Baranek, 2002; Dawson & Watling, 2000) and supplement use (Salman, 2002).

It is possible that a lack of information, or poorly disseminated information regarding evidence-based treatments for children with DS contributes to the continued use of non-evidence based treatments by treatment providers and caregivers. Additionally, high motivation to improve quality of life for their children may motivate caregivers to try treatments based upon advertisement or perceived availability, regardless of empirical support (Prussing et al., 2005).

Our results indicate caregivers of children with DS were using an average of five different treatments simultaneously. While multiple

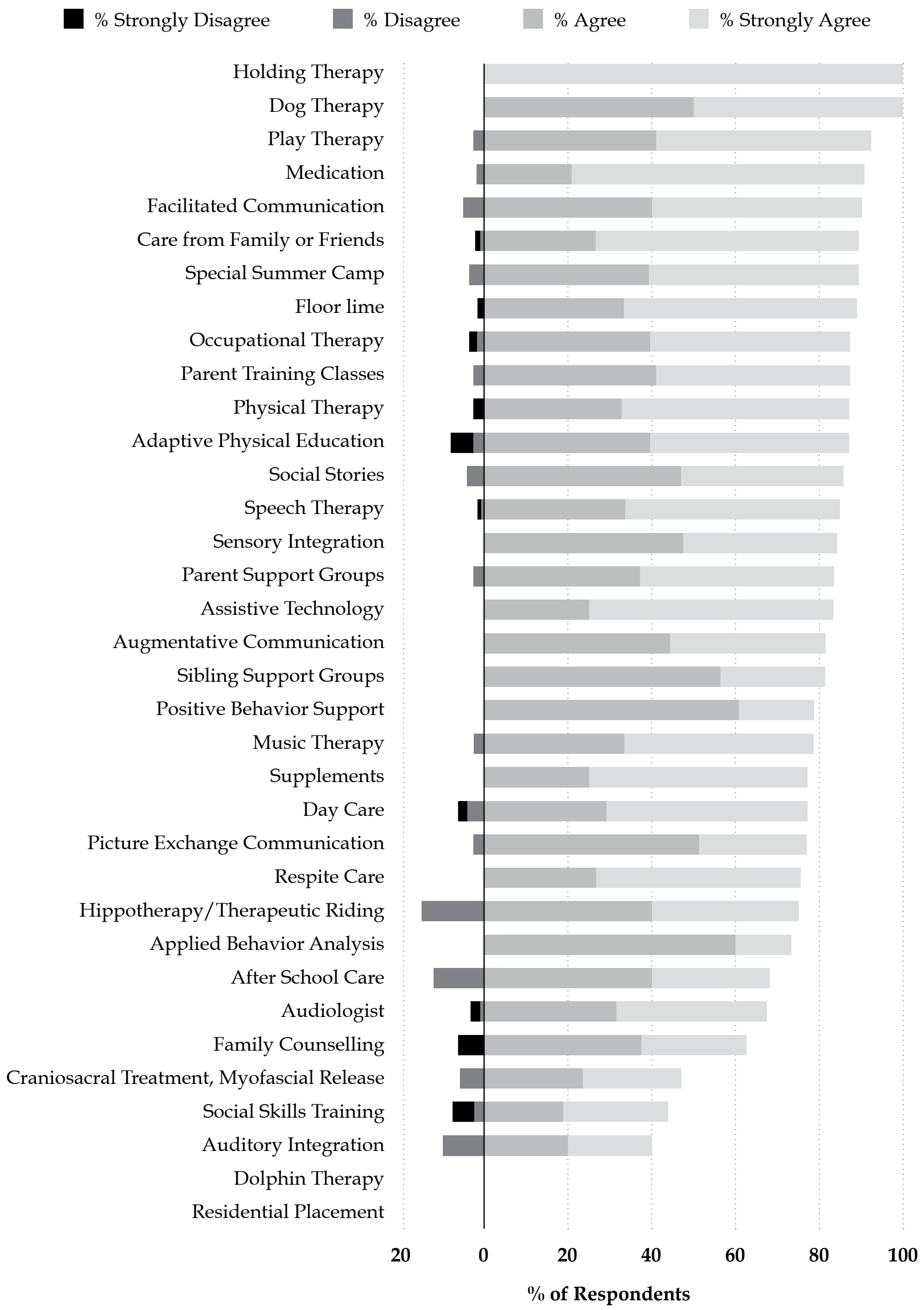

Figure 3. *Responses of participants who use/have used treatment to the statement, "This treatment was effective and contributed to my child's growth." Note: In some cases a primary caregiver did not indicate (a) current, (b) past, or (c) never for a particular treatment. Such omissions were classified as missing data. As a result of missing data, the sample sizes varied across treatment. Data for neither agree/nor disagree is not represented in the figure. The lack of information for dolphin therapy and residential therapy reflects all caregivers indicating neither agree/nor disagree.*

Table 1. Demographic Characteristics of the Primary and Secondary Caregiver and Children with Down Syndrome

	Number	*Percent*	*Mean*	*Standard Deviation*
Primary Caregiver				
Country of Residence				
United States	81	50.0		
Canada	16	9.9		
Ireland	23	14.2		
United Kingdom	6	3.7		
Australia	5	3.1		
Andorra	1	0.6		
China	1	0.6		
France	1	0.6		
Greece	1	0.6		
Poland	1	0.6		
Romania	1	0.6		
South Africa	1	0.6		
Gender				
Female	121	87.7		
Male	17	12.3		
Age (years)			41.5	9.4
Race/Ethnicity				
White	128	92.8		
Black or African American	3	2.2		
Asian	3	2.2		
American Indian or Alaska Native	1	0.7		
Other	3	2.1		
Relationship Status				
Married	112	81.2		
Divorced	11	8.9		
Never married	9	5.6		
Separated	4	2.5		
Widowed	2	1.4		
Educational Level				
Less than high school	2	1.4		
High school graduate	9	6.5		
Educational level beyond high school	127	78.4		
Children in household				
One	46	33.3		
Two	47	34.1		
Three	33	23.9		
Four	6	4.3		
Five	6	4.3		

Table 1. Demographic Characteristics of the Primary and Secondary Caregiver and Children with Down Syndrome (continued)

Secondary Caregiver				
Gender				
Female	97	86.6		
Male	15	13.4		
Age (years)			43.7	8.6
Race/Ethnicity				
White	102	91.1		
Black or African American	4	3.6		
Asian	2	1.8		
Other	4	3.6		
Relationship Status				
Married	105	93.8		
Divorced	4	3.6		
Never married	2	1.8		
Separated	1	0.9		
Educational Level				
Less than high school	2	1.8		
High school graduate	13	11.6		
Educational level beyond high school	97	86.6		
Children with DS				
Gender				
Males	74	53.6		
Females	64	46.4		
Age (years)			7.4	5.0
Race/Ethnicity				
White	117	84.8		
Black or African American	5	3.6		
Asian	4	2.9		
American Indian or Alaska Native	2	1.4		
Native Hawaiian or Pacific Islander	1	0.8		
Other	9	6.5		
Has DS Plus One or More Additional Diagnoses	31	22.5		
Number of Children with DS in Household				
One child with DS	135	97.8		
Two or more children with DS	3	2.2		

Note: Primary caregivers completed the survey. Secondary caregiver information was reported by the primary caregiver.

Table 2. Diagnoses Reported by Caregivers of Children with DS.

Diagnosis	*Number*	*Percentage*
Only Down syndrome	107	77.5
Co-occurring diagnosis	31	22.5
Autism spectrum disorder	6	19.4
Apraxia	3	9.7
Attention-deficit/ hyperactivity disorder	3	9.7
Sensory processing disorder	3	9.7
Sleep apnea	3	9.7
Anxiety disorders	2	6.5
Cerebral palsy	2	6.5
Epilepsy	2	6.5
Cystic fibrosis	1	3.2
Dyslexia	1	3.2
Ehler-Danlos syndrome	1	3.2
Global delayed learning	1	3.2
Graves' disease	1	3.2
Heart defect	1	3.2
Hashimoto's disease	1	3.2
Hydrocephalus	1	3.2
Hypothyroidism	1	3.2
Leukemia	1	3.2
Nystagmus	1	3.2

Note: In some cases a caregiver reported multiple co-occurring diagnoses for a child. As a result the sum of percentages is greater than 100%.

treatments may have positive effects if those treatments are evidence-based, as one treatment may bolster the effects of another, in some cases multiple treatments may be contraindicated. Additionally, the use of multiple simultaneous therapies poses a methodological challenge, as the effects of evidence-based treatments may be masked or misattributed to non-evidence-based treatments. For example, caregivers often seek evidence-based treatments targeting speech, language, motor skills, communication and challenging behaviour (e.g., speech and language therapy; Kumin, 2012; Rondal & Buckley, 2003; physical therapy; and applied behaviour analysis; Bauer, Jones, & Feeley, 2014; Feeley & Jones, 2006; Neil & Jones, 2016), coupled with treatments that are not evidence-based (e.g., facilitated communication, sensory/auditory integration, and craniosacral/myofascial; Ernst, 2012). Confounding effects across treatments may account for positive caregiver ratings across treatments regardless of empirical support, as caregivers may misattribute treatment gains to non-evidence-based treatments.

The average number of currently used treatments varied as a function of the child's age, race, and gender. Female children with DS were currently receiving more treatments than male children with DS. While research on gender differences in DS is scarce, one study suggests that girls with DS score higher on language measures (Berglund, Eriksson, & Johansson, 2001). Thus, it is paradoxical that girls receive more interventions than boys, despite evidence (albeit preliminary) that boys display greater impairments. Future research and interventions should seek to expand interventions to target boys with DS who may be of greater need, as well as to better understand gender differences in DS presentations and treatments.

Additionally, white caregivers reported significantly more treatments than caregivers of colour when their children were 0–6 years old, a pattern which reversed among children 7–12 years old, before equalizing at ages 13–18. Although few people of colour participated in the study, cultural differences may have impacted our results. For example, people of colour tend to be more collectivists (i.e., they keep concerns within families), which may explain why they did not access early intervention like white caregivers who generally tend to seek outside expertise in addition to family support. Furthermore, it may be that the caregivers are not informed about the ways to access early intervention. However, it is possible that these results are an artifact of our non-representative sample, which was largely comprised of white children (84.8%). This limita-

Table 3. Rank Order of Treatments in Terms of Percentage of Primary Caregivers Reporting Use

No.	*Treatment Name*	*% Currently Using*	*% Used in the Past*
1	Speech Therapy	73.0	19.7
2	Care From Family or Friends	57.7	20.8
3	Occupational Therapy	51.1	35.8
4	Physical Therapy	50.4	42.1
5	Audiologist	39.1	34.6
6	Parent Support Groups	38.2	25.2
7	Medication	35.1	9.2
8	Supplements	33.8	6.9
9	Adaptive Physical Education	22.5	9.3
10	Assistive Technology	19.4	11.6
11	Floortime	19.1	32.8
12	Respite Care	18.9	15.9
13	Social Stories	18.1	23.6
14	Social Skills Training	18.0	11.7
15	Day Care	15.9	24.2
16	After School Care	14.3	8.3
17	Picture Exchange Communication	13.8	19.2
18	Music Therapy	13.7	19.8
19	Positive Behaviour Support	13.2	10.9
20	Augmentative Communication	12.3	11.5
21	Play Therapy	12.2	19.1
22	Facilitated Communication	9.3	9.3
23	Special Summer Camp	9.2	14.5
24	Parent Training Classes	6.9	24.4
25	Dog Therapy	6.9	2.3
26	Craniosacral Treatment, Myofascial Release	6.1	8.4
27	Hippotherapy/Therapeutic Riding	3.8	13.0
28	Sensory Integration	3.8	12.9
29	Sibling Support Groups	3.1	10.0
30	Applied Behaviour Analysis	3.1	11.0
31	Family Counselling	2.3	13.1
32	Auditory Integration	1.5	6.9
33	Holding Therapy	0.8	1.5
34	Dolphin Therapy	0	1.5
35	Residential Placement	0	0.8

Table 4. Analysis of Variance for Total Number of Current Treatments (n = 133)

Source	*df*	*F*	*p*
Age Category	2	1.03	.363
Race	1	2.08	.152
Gender	1	5.25*	.024*
Age Category×Race	2	5.23*	.007*
Age Category×Gender	2	1.45	.238
Race×Gender	1	.623	.432
Age Category×Race×Gender	2	.639	.530
Error	121	(.063)	
Total	133		

Note: Analyses based upon log10-transformed data; Value in parentheses represents the mean square error; "" p is significant; "×" refers to test of interaction between sources.*

tion may impact the generalizability of our findings regarding race. Thus, the following results while preliminary warrant further investigation to help clinicians and researchers more effectively disseminate information and services to families from diverse racial/ethnic backgrounds.

Albeit preliminary and part of a scarce pool of research, our results regarding rates of treatment participation among children with DS are consistent with other developmental disabilities. For example, children with autism spectrum disorder (ASD) generally have higher mean number of current and past treatments (7 and 8 respectively) than children with DS (Green et al., 2004). It may be that children with ASD are referred for treatment more frequently due to challenging behaviours and noteworthy social impairments, whereas children with DS may appear to only have significant language impairments (Sigman et al., 1999). For children with ASD speech therapy, visual schedules, sensory integration and applied behavior analysis were the four most commonly used treatments (Green et al., 2004). In another study, caregivers showed strong support for parent training, speech therapy, sensory integration and discrete trial teaching (Hume et al., 2005). Only speech therapy was common among the most frequently used treatments for children with DS.

This study has several limitations. Caregivers of children with DS may not be reliable or accurate evaluators of their child's actual developmental outcomes and future research is needed to determine how perceptions of outcomes relate to valid measures of outcomes and treatment selection. The sample selection method also presents limitations. Participants in this study may reflect a non-representative subgroup of families with children with Down syndrome, as all participants had access to the internet and were recruited from DS advocacy agency websites and mailing lists. This is reflected in the lack of variability in gender and educational level of the participants. Participants may also be more informed regarding treatment treatments as they received regular informational mailings and access advocacy sites regularly. Response bias is another potential limitation in this study, as we were unable to assess caregiver understanding of described treatments listed.

In summary caregivers of children with Down syndrome access a wide variety of treatments with and without empirical support for their use. Caregivers of children with Down syndrome need access to educational materials surrounding specific treatments, presented in a manner that is easily understood. The number of treatments currently being used by caregivers varied with characteristics of the child with Down syndrome indicating access to information and services varies with child characteristics. There is a need for additional research to understand how caregivers select treatment for their children with Down syndrome. Identifying the variables that influence decision-making will help inform promotional practices aimed at increasing the use of empirically supported treatments among children with Down syndrome.

Key Messages From This Article

People with disabilities. If you are seeking help, you deserve to have a treatment that works and is a good fit for you as a person.

Professionals. Treatment for children with Down syndrome should be evidence-based, Information about the effectiveness of treatments should be provided to families to assist in treatment decision making.

Policymakers. Families of children with Down syndrome are accessing a wide variety of effective and noneffective treatments. Increased policies are needed that specify the use of evidence-based treatments for children with Down syndrome.

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BRIEF REPORT: Bystander Perceptions of an Exercise Program for Adults With Autism Spectrum Disorder and an Intellectual Disability Within a University Setting

Authors

Rebecca-Jane McAllister,
Kelly Carr,
Chad A. Sutherland,
Nadia Azar,
Sean Horton

Adapted Physical Exercise (APEX) Research Group,
Department of Kinesiology,
University of Windsor,
Windsor ON

Correspondence

hortons@uwindsor.ca

Keywords

autism spectrum disorder (ASD),
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bystander,
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perceptions

Abstract

Individuals with disabilities are less likely to partake in community-based recreation activities if they perceive negative attitudes from other community members. This study sought to evaluate the impact of an adapted physical exercise (APEX) program for adults with autism spectrum disorder and intellectual disability on members of a university fitness facility (i.e., bystanders). Seven bystanders (all university students) who had been present during APEX training sessions participated in a semi-structured interview. Emergent themes and sub-themes indicated that inclusion of individuals with disabilities within a university fitness facility also benefits program bystanders.

The prevalence of autism spectrum disorder (ASD) has risen dramatically in recent years, with nearly an 80% increase in ASD diagnoses between 2002 and 2008 (Elsabbagh et al., 2012; Centers for Disease Control and Prevention [CDC], 2012). In 2010, one in 68 children were diagnosed with the disorder (CDC, 2014). Within Canada, the incidence of ASD across various regions is increasing annually between 9.7% and 14.6% (Ouellette-Kuntz et al., 2014). Moreover, according to one source, 31% of ASD cases co-occur with intellectual disability (ASD-ID; CDC, 2014). Due to this rapid rise in prevalence rates, finding effective ways of integrating individuals with ASD into the community is paramount.

Social inclusion and interaction between individuals with ASD and their peers is a promising area of research (Simplican, Leader, Kosciulek, & Leahy, 2015; Sutherland, Ivey, & Woodruff, 2013; Walton & Ingersoll, 2013). Much of the current literature highlights the importance of exercise interventions to help reduce stereotypical behaviours, as well as how peer-mediated interventions through inclusive environments help those with ASD (DiSalvo & Oswald, 2002; Koegel, Vernon, Koegel, Koegel, & Paullin, 2012; Petrus et al., 2008). It is believed that peer involvement increases the number of available intervention agents, fosters inclusion in school settings, and helps to build relationships between individuals with disabilities and their peers (Walton & Ingersoll, 2013). Peer-mediated interventions have been found to have a positive impact on several social and communication behaviours in individuals with ASD (Walton & Ingersoll, 2013).

Recent research suggests that people with disabilities are less likely to partake in community-based recreation activities if they perceive negative attitudes from others in the community (Choi, Johnson, & Kriewitz, 2013). Importantly, perceived social acceptance and frequency of leisure participation are positively and meaningfully correlated in individuals with disabilities (Choi, Johnson, & Kriewitz, 2013; Devine & Dattilo, 2001). Less is known about the impact that interventions have on others, specifically those who are not the primary target of the intervention. Therefore, the purpose of this qualitative inquiry was to determine the impact of the adapted physical exercise (APEX) program on program bystanders. To our knowledge, this is the first study to examine the integration of adults with ASD-ID within a university fitness facility and the impact of this integration on other gym members (i.e., the "bystanders" of the intervention). Given our intention to understand perceptions of disability, and the effect of integration on such socially prevalent assumptions, we situate this research within critical disability theory. In doing so, a social constructionist epistemology is adopted where we recognize disability as a social phenomenon that is constructed through interactions between humans and their world (Chadwick, 1994; Crotty, 1998; Pothier & Devlin, 2006).

Methods

Participants

An APEX program hosted at the University's campus fitness facility provided a 12-week whole-body circuit-training regimen for 14 adults with ASD-ID (age range = 18–62 years; 2 females; IQ scores from previous clinical assessment = 20 to 70). The program took place during the facility's off-peak attendance times, and each participant was paired with a personal trainer (1:1 ratio). The program featured staggered participation, where small groups of participants with ASD-ID and their personal trainers were exercising in different parts of the fitness facility (e.g., four on cardio machines, four on strength machines, and four in the field house playing sports/games). Considering this set-up, bystanders were exposed to up to eight people with ASD-ID, plus their personal trainers, within the same fitness space at a given time. Over the 12 weeks, two of the co-authors (RJM and KC, who attended every session) approached gym members (*n* = 6) and staff (*n* = 1) who were identified as being regularly present during the APEX program training sessions to distribute an informational flyer about the study. All those who were approached agreed to participate (3 males, 4 females; age range 19–49 years; mean age = 28.9 years; all university students) and provided informed consent. Ethics clearance for this research project was obtained through the University of Windsor Research Ethics Board.

Interview Format

Each participant took part in a brief, semi-structured interview. The interview guide contained questions that aimed to determine any potential impact the APEX program had on these bystanders, their time in the facility, and their workout routines. The questions also attempted to determine any changes in the perceptions these program bystanders had towards individuals with ASD-ID after being indirectly exposed to the APEX program. Although this interview guide provided the basic topics to be discussed, the semi-structured interview permitted the exploration of new topics that emerged during individual interviews (Patton, 2002). Details about the semi-structured interview are available upon request.

Analysis

All interviews were audio-recorded and transcribed verbatim by the lead author. In accordance with hierarchical content analysis, an inductive approach was used in which quotes from the interviews were coded as meaning units (Côté, Salmela, Baria, & Russell, 1993). A meaning unit is defined as a "…segment of text that is comprehensible by itself and contains one idea, episode or piece of information" (Côté et al., 1993, p. 131). To illustrate, a meaning unit outlined in Table 1 on the following page includes *It didn't [affect my personal workout], no more than anybody else.* According to the definition provided by Côté et al. (1993), this segment of text can be classified as a meaning unit as it is a single idea expressed by a participant that is understandable by itself. All meaning units were then compared and organized based on common

Table 1. Overview of Themes and Sub-Themes of Bystander Interviews

Theme	*Sub-Theme*	*Meaning Units*
The significance of inclusivity	The importance of exposure	"I think it would be great if more students could be exposed to it [the APEX program]… Not just people being involved in the research, but just being a bystander around it… The more people are exposed to those with disabilities, the more they'll understand, the less likely they are to discriminate."
		"The more times [you're exposed to individuals with disabilities] in any sort of situation, the less likely someone is going to feel uncomfortable or feel judgmental about it in a different situation like at work or school."
	Supportive of inclusive fitness facilities	"If I had a gym that did not allow that [the participation of individuals with ASD-ID], I probably wouldn't join that gym."
		"I love gyms that are really focused on the people of their gym."
Effect on bystanders' personal workouts	Any other day at the gym	"Basically the same [a program participant's vocalization] as the jock people that are screaming when they're lifting. It's basically the same, or actually less annoying."
		"It didn't [affect my personal workout], no more than anybody else."
	A source of motivation	"It pushed me because if I was having a tough time in my workouts, I would look and see how hard these individuals [with ASD-ID] were pushing themselves and I was like 'well if they are pushing themselves to do that… Then you can do this today as well, [you can] get through this.'"
		"When they [a gym bystander] would get a smile from one of your participants [with ASD-ID] they would be in a better mood, so it was great. It was almost like a contagious thing."

features in order to be grouped into sub-themes (Côté et al., 1993; Tesch, 1990). These sub-themes were then analyzed further and grouped into distinct themes based on similarities (Côté et al., 1993; Tesch, 1990). The sub-themes and themes remained flexible during analysis and were refined and debated amongst the co-authors until a classification system evolved that best represented the qualitative material while limiting any overlap between themes.

Results

Two themes and four sub-themes were established from the bystander interview responses. The first theme was *the significance of inclusivity,* which included the sub-themes *the importance of exposure* and *supportive of inclusive fitness facilities*. The second theme was the *effect on gym bystanders' personal workouts*, which included the sub-themes *any other day at the gym* and *a source of motivation*. Please refer to Table 1 for an overview of these themes, sub-themes, and meaning units.

Discussion and Conclusion

Our findings suggest that the attitudes of members of our university fitness facility are positive and encouraging regarding the integration of individuals with disabilities, specifically

ASD-ID, exercising within a university gym environment. These bystanders recognized the importance of exposure to individuals with disabilities in order to become more familiar and comfortable, noting that exposure would likely reduce discriminatory behaviours and attitudes as well as improve perceptions of the capabilities of those with disabilities. Furthermore, bystanders identified that their time at the gym was unaffected by the APEX program participants. In some cases, participants identified preferring the presence of individuals with ASD-ID compared to stereotypical gym members.

A potential limitation to this study is the relative homogeneity of the sample. University students may not represent the views of the broader community or those held by members of fitness facilities outside of a university environment (Yazbeck, McVilly, & Parmenter, 2004). Despite this, the results are encouraging and suggest that further research incorporating more diverse samples is warranted. The inclusion of individuals with disabilities within a university fitness facility appears to have a positive impact, with mutual benefits for individuals with disabilities and the program bystanders. This research supports the findings of Brasile (1990), who stated that the inclusion of individuals with disabilities into the general community promotes a better understanding of the broad scope of their capabilities. This research will provide foundational information for future studies on how the inclusion of people with disabilities in a community-based exercise facility is perceived by other community members.

Key Messages From This Article

People with disabilities. Participating in an exercise program can benefit your physical and mental health. However, by exercising within a community gym, you are also providing a positive impact on other gyms users. Specifically, you are helping community members to better understand your capabilities, which has the potential to reduce discriminatory behaviours and attitudes towards people with disabilities.

Professionals. It is important for community fitness facilities to offer exercise programming for people with disabilities during normal hours of operation. By providing this inclusive environment, community members are given an opportunity to witness the capabilities of people with disabilities, which can lead to a more inclusive community.

Policymakers. Policy to support exercise programs within community fitness facilities for people with disabilities should be established. Not only will it enhance the health and well-being of people with disabilities, it also provides an opportunity for other community members to learn about the capabilities of people with disabilities.

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Author Note

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CASE REPORT: Intervention Evaluation of Trial-Based Functional Analyses in School

Authors

Sarah M. Dunkel-Jackson,[1,2]
Kara Kenney,[1,3]
Shannon Borch,[1]
Cheryl Neely Neveu[1]

[1] Kinark Child and Family Services,
Markham ON

[2] Present address:
Seneca College,
King Campus,
King City ON

[3] Present address:
Durham Catholic District School Board,
Oshawa ON

Correspondence

sarah.dunkel-jackson@senecacollege.ca

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trial-based functional analysis,
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classrooms,
demand fading,
autism spectrum disorder

Abstract

While functional analysis is widely viewed as the gold standard assessment technique to determine the function, or purpose, of a challenging behaviour, a number of barriers exist to conducting such assessments in natural settings such as classrooms. The trial-based functional analysis (TBFA) is a promising modification which embeds assessment trials throughout on-going daily activities in the natural environment. TBFAs may be more conducive to natural settings as they minimize risk by ending trial segments after a single occurrence of the target behavior, increase ecological validity, and minimize disruptions to the daily schedule. Researchers have systematically evaluated the utility of trial-based functional analyses (TBFA) on the development of effective, function-based interventions. The purpose of the current study was to contribute to this growing body of evidence by conducting two TBFAs for a student with autism spectrum disorder in a publicly funded school setting and evaluating the effects of a function-based intervention informed by the TBFA results. A demand fading protocol (the removal of all instructions, followed by their gradual reintroduction) was implemented to address the escape-maintained challenging behaviour (behaviours used to get out of an undesired activity). Data indicated increased engagement with academic stimuli and decreases in challenging behaviour as a result. The generalization of these results with novel staff and novel tasks was also demonstrated. These results support the utility and feasibility of TBFAs to assess behavioural function and the resulting ABA approaches to reduce challenging and disruptive behaviour in publicly funded school settings.

Functional analysis (FA) as an effective means of identifying functions of challenging behaviours is well-documented in the literature (e.g., Hanley, Iwata, & McCord, 2003; Iwata & Dozier, 2008). By identifying the maintaining variables of challenging behaviours (e.g., access to attention, escape from demands, tangible items/activities, sensory stimulation), effective, function-based interventions can be utilized rather than ineffective, default technologies (Mace, 1994). A function-based intervention would incorporate the maintaining variable (or reinforcer for the challenging behaviour) by reducing the "motivation" to access the identified reinforcer, minimizing access to that reinforcer contingent on the challenging behaviour, and/or teaching an alternative way to access that reinforcer. The traditional FA methodology involves repeated and extended (e.g., 5- to 15-minute conditions) exposure to the hypothesized maintaining variables in a highly controlled setting.

However, due to a number of potential barriers limiting the use of traditional FAs in schools (e.g., assessment duration, assumed risk, specialized environmental conditions) (e.g., Bloom, Iwata, Fritz, Roscoe, & Carreau, 2011), several researchers (e.g., Bloom et al., 2011; Sigafoos & Saggers, 1995) have demonstrated the use of a modified version, the trial-based functional analysis (TBFA) (see Rispoli, Ninci, Neely, & Zaini, 2014 for a review). During a TBFA, participants are repeatedly exposed to brief control (i.e., abolishing operations for the putative reinforcer in effect) and test (i.e., establishing operation for the putative reinforcer in effect) conditions in the natural setting from which conclusions about the function can be drawn (e.g., Austin et al., 2015; Bloom et al., 2011). For instance, in order to test attention as the potential reinforcer of challenging behaviour, the control condition would consist of free access to attention (no establishing operation to evoke the behaviour if maintained by attention) and the test condition would consist of diverted attention so as to evoke the behaviour if attention is the reinforcer (see Table 1 for more details). TBFAs may be more conducive to natural settings as they mitigate risk by ending trial segments after a single occurrence of the target behaviour and minimize disruptions to the daily routine as trials are embedded into ongoing daily activities. Furthermore, conducting the assessment in the setting of interest may have the added benefit of capitalizing on context-specific idiosyncratic variables and, therefore, enhancing the ecological validity of the results.

Another promising modification in the FA literature involves the use of latency-based measures (e.g., Thomason-Sassi, Iwata, Neidert, & Roscoe, 2011) which can be indicative of rate of responding. Latency FAs look at how long after a segment begins (i.e., an establishing operation is put in effect [e.g., attention diverted, demands placed]), the challenging behaviour occurs as opposed to how many times a behaviour occurs in a set amount of time. A shorter latency between the start of a segment and the occurrence of the challenging behaviour may be indicative of a higher rate of behaviour in a more traditional assessment. Using latency as a measure mitigates risk by ending conditions after a single occurrence of the target behaviour while maintaining the validity of results. Researchers in school settings have also begun to evaluate the utility of TBFAs on informing function-based interventions such as functional communication training (e.g., Lambert, Bloom, & Irvin, 2012), non-contingent reinforcement (e.g., offering preferred activities throughout the day independent of whether a target behaviour occurred) (Bloom et al., 2013), and differential reinforcement of other behaviour (DRO) procedures (e.g., delivering a reinforcer after the absence of a target behaviour) (Austin, Groves, Reynish, & Francis, 2015). Further opportunities exist to closely examine the utility of TBFAs on the development of additional interventions that effectively decrease challenging behaviours and provide students opportunities for success in schools. In this study, demand fading was identified as a function-based intervention as it is characterized by minimizing then slowly re-introducing demands so as to remove the "motivation" to engage in a challenging behaviour to avoid demands. Furthermore, escape from demands and access to tangible reinforcers were available for task completion providing an alternative means to access these reinforcers. This study replicates and extends previous research by using results of two TBFAs (on swearing and head banging) with latency as a secondary measure to allow for a more in-depth analysis. Results were then used by the intervention team to inform the selection of demand fading as a function-based intervention for escape-maintained behaviour to decrease a child's challenging behaviours and increase engagement with school tasks. The assessment of the generality of intervention effects also extends this valuable line of research.

Method

Overview

In general, consultants, educators, and the family collaborated on an assessment and intervention process guided by the key principles of applied behaviour analysis (ABA) (see Figure 1). First, baseline data were collected to identify the extent to which challenging behaviour interrupted the participant's learning (e.g., completing zero academic demands). Next, functional behaviour assessments, including questionnaires and observations, were conducted to develop hypotheses about why the challen-

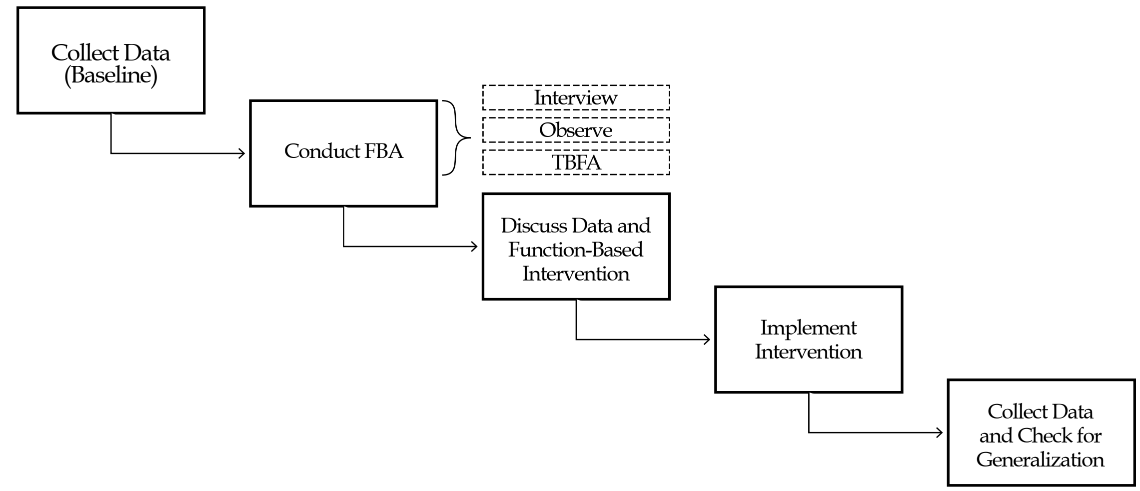

Figure 1. Flow chart outlining the general assessment and intervention process

ging behaviours occurred (i.e., function) and to set up conditions of a more direct assessment (i.e., TBFA). During the TBFA, consultants and educators tested their hypotheses by exposing the participant to several trials that were interspersed throughout the school day. Each trial consisted of a 1-minute control segment where the potential reinforcer was freely available (e.g., access to teacher attention) immediately followed by a 3-minute test segment where the potential reinforcer was removed (e.g., attention removed; see Table 1 for an outline of each condition). If the participant engaged in the target behaviour during the control segment, staff initiated the test segment. If the target behaviour occurred during the test segment, the potential reinforcer (e.g., attention) was provided and the segment was terminated. During both the control and test segments, staff recorded the occurrence or non-occurrence of the target behaviour. Staff also recorded that latency in seconds (i.e., how many seconds from the beginning of the trial to the occurrence) to the target behaviour. The intervention team then analyzed and discussed the data which were presented as the percentage of trials during which the target behaviour occurred across each hypothesized function (i.e., condition) and latencies. Based on the results of this assessment, the intervention team developed and implemented a function-based intervention to decrease the challenging behaviours and teach appropriate replacement behaviours. Generalization across novel tasks and staff was also assessed.

Participant

The participant, "Liam, pseudonym" was a 9-year-old, male student diagnosed with autism spectrum disorder (ASD) receiving consultation-based Connections for Students (CFS) services while transitioning from a community-based, intensive behavioural intervention (IBI) classroom to a publicly funded special education classroom in Ontario. As identified by the Verbal Behaviour Milestones Assessment and Placement Program (VB-MAPP; Sundberg, 2008), Liam had met 91% of milestones, with barriers of behaviour problems, instructional control, and sensory defensiveness. Standardized cognitive and adaptive assessments completed approximately 6 months prior to participation in the study indicated a mild delayed nonverbal IQ (1st percentile) and moderately delayed verbal IQ (< 1st percentile) on the Stanford-Binet Intelligence Scale (5th Edition) as well as a low adaptive behaviour score (1st percentile) on the Vineland Adaptive Behavior Scales (2nd Edition). Informed consent to conduct the assessment and intervention as well as to present and publish the data was obtained from Liam's parents and the school approved the research project and its dissemination.

Setting and Materials

TBFA sessions were conducted in Liam's classroom (~30'x20'), gymnasiums, hallway, and library. School staff included one teacher and four educational assistants (staff) shared across six students with Liam requiring one-to-one support to manage his challenging behaviours. Some baseline and all intervention sessions were conducted in Liam's individual workspace (~5' × 7') that was segregated from his peers by a physical boundary enclosed on three sides. Academic worksheets and task materials developed by the teacher based on the Ontario academic curriculum and reinforcers were also used.

Dependent Variables and Measurement

As termed by the school team and parent, *swearing* was defined as Liam vocally saying profanities, discussing nudity, or inquiring if he could harm others. *Head banging* was defined as Liam hitting his head on an object (e.g., basketball), surface (e.g., wall), person, or himself (e.g., knee to his head) which may produce an audible noise and may leave an abrasion or contusion.

During the TBFA, authors collected data on the occurrence of the challenging behaviour. The percentage of trials that Liam engaged in head banging or swearing was then calculated for each of the conditions by dividing the total number of trials during which challenging behaviour occurred by the total number of trials conducted for the condition and multiplying by 100. Based on the utility of latency measures in Thomason-Sassi et al. (2011), the first author also collected data on the latency to challenging behaviour. By recording the number of seconds from the start of the segment to the initiation of challenging behaviour, response latencies were then visually analyzed to identify if particular conditions/idiosyncratic variables (e.g., task difficulty, location in school) were associated with longer/shorter latencies.

During baseline and intervention phases, but not during the TBFA, the consultant and/or staff collected data on Liam's completion of a specified number of worksheet tasks (e.g., writing name, writing name and answering 1 question) with or without prompts. Staff provided prompts for task completion if Liam requested this (i.e., manded) "help" and/or if Liam did not respond with the correct answer. If Liam complied with prompts within 10 seconds, this was considered completing tasks and if Liam refused to comply with the task after 10 seconds (e.g., "No!" "Can I go to the small gym?") and/or engaged in challenging behaviour, the trial ended. For each trial, staff recorded the number of tasks on the worksheet that Liam completed as well as the occurrence of challenging behaviour.

Trial-Based Functional Analysis

Functional Behaviour Assessment (FBA). Prior to conducting the TBFAs, the intervention team reviewed the results of indirect and descriptive FBAs to help inform experimental conditions. The Questions About Behavioral Function (QABF; Matson & Vollmer, 1995) questionnaire was completed separately by the consultant with three school staff (one teacher, two educational assistants) as informants which generated hypothesized functions including attention, tangible, non-social stimulation, and escape. Although descriptive data have not always demonstrated concordance with FAs for certain behaviours (e.g., Thompson & Iwata, 2007) but have demonstrated adequate concordance for other behaviours (e.g., Borrero, England, Sarcia, & Woods, 2016), the consultant also collected Antecedent-Behaviour-Consequence (ABC) data to potentially narrow the number of hypothesized functions. While the results of the ABC data were inconclusive, they did provide specific information to develop idiosyncratic escape, tangible, and attention experimental conditions within the classroom and school setting (see below).

Methods. Two separate TBFAs based on methods and recommendations from previous research (e.g., Austin et al. 2015; Bloom et al., 2011; Thomason-Sassi et al., 2011) were conducted for swearing and head banging. As in Austin et al., each trial consisted of a control segment during which the potential reinforcer was freely available, followed by a test segment during which the potential reinforcer was removed. If the challenging behaviour occurred during the control segment, no programmed consequence was provided and the test segment was initiated. Based on the recommendation from Bloom et al., the TBFA conditions were divided into a 1-minute control segment followed by a 3-minute test segment to expose the student to the possible establishing operation for longer durations to potentially improve accuracy (e.g., discrimination of the contingencies). A summary of the antecedent and consequent procedures of each trial type can be found in Table 1.

During each condition, the consultant provided no programmed consequences for other challenging behaviour or appropriate behaviour. The authors led the assessment and staff participated as a "therapist" and/or observed during trials. To minimize disruption and maximize the validity of the results, trials were interspersed throughout the day as naturally occurring opportunities presented themselves with relevant antecedent variables in effect (e.g., task demand trials during typical work time, tangible trials as Liam showed interest). The TBFAs were completed in approximately 4 hours (swearing) and 3.5 hours (head banging) across 1 day each within the same week.

The authors conducted 10 trials of each condition and analyzed whether further trials would be required to confidently interpret the results. This intermediate analysis was conducted because the team's FBA results suggested that challenging behaviour was potentially sensitive to all contingencies and, specifically, multiple escape contingencies. For example, staff may have hypothesized "attention-seeking" as the function because staff were always near Liam and frequently provided vocal verbal reprimands (attention). However, the authors pointed out that (a) staff always being near

Table 1. TBFA Trial Procedures by Trial Type

	Attention	*Escape*	*Tangible*
Antecedent Conditions	*Control*: Constant attention in the form of eye contact, occasional comments, and compliance with requests for attention *Test*: Attention removed ("I have to work" or "I'm busy") and turning away from participant	*Control*: No demand placed or instructional materials presented *Test*: (a) Task demands (head banging, swearing) (b) Instructions to engage in a group activity (head banging), or (c) Social demands (e.g., consultant-initiated conversation about neutral topic (swearing)	*Control*:Preferred items (e.g., basketball, iPad®, maps) as identified by a preference assessment *Test*: Preferred item removed ("My turn" or "All done")
Consequence Conditions	*Control*: No programmed consequences to the challenging behaviour, test segment initiated *Test*: Contingent on the target behaviour, the consultant immediately provided verbal attention (e.g., "Careful!," "I won't speak with you if you say those words") and ended the trial.	*Control*: No programmed consequences to the challenging behaviour, test segment initiated *Test*: Contingent on the target behavior, the consultant immediately removed materials and demands (e.g., "Ok, you don't have to work." "You need a break"), moved away from participant, and ended the trial.	*Control*: No programmed consequences to the challenging behaviour, test segment initiated *Test*: Contingent on the target behavior, the consultant immediately returned the item (e.g., "Sorry, you weren't done") and ended the trial.

Liam could also be a conditioned aversive stimulus (escape), (b) reprimands delay task demands (escape), (c) there was no engagement in collateral "attention-seeking" behaviour such as making eye contact and looking for a "reaction" to comments, and (c) Liam was observed to frequently mand for attention with a more appropriate topography (i.e., form, or what the behaviour looks like). Therefore, this allowed the contributed hypotheses of each team member to be directly tested and the analysis would not need to be extended unnecessarily. Therefore, 20 trials were conducted for escape task demands (head banging, swearing), escape group demands (head banging), tangible (swearing, head banging) and 10 trials were conducted for attention (head banging, swearing), escape social demands (swearing).

Attention. During the control segment, the consultant was seated near Liam and provided constant attention in the form of eye contact, occasional comments, and compliance with mands for attention. During the test segment, the consultant removed attention by saying, "I have to work" or "I'm busy" and turning away from Liam. Contingent upon the target behaviour, the consultant immediately provided verbal attention (e.g., "Careful!," "I won't speak with you if you say those words.") and ended the trial.

Escape. During the control segment, Liam was seated without access to materials and the consultant was nearby but provided no demands and no attention. During the various test segments, the consultant provided (a) task demands (head banging, swearing), (b) instructions to engage in a group activity (head banging), or (c) social demands (e.g., consultant-initiated conversation about neutral topic; swearing). Contingent upon the target behaviour, the consultant immediately removed materials and demands (e.g., "Ok, you don't have to work." "You need a break."), moved away from Liam, and ended the trial.

Tangible. During the control segment, Liam was provided with preferred items (e.g., basketball, iPad®, maps) as identified by a preference assessment (i.e., interview conducted by consultant with the staff and parent) and the consultant was nearby but provided no demands and no attention. During the test segment, the consultant removed the preferred item and said, "My turn" or "All done." Contingent upon the target behaviour, the consultant immediately returned the item, said, "Sorry, you weren't done.," and ended the trial.

Function-Based Intervention Evaluation

Baseline. During scheduled independent tasks, school staff or consultants provided Liam with task materials (e.g., final version of the worksheet with full response requirement, pencil, eraser) and instructions. Consequences for completing the task would have included access to preferred items (tangible) identified through a preference assessment (e.g., maps, iPad®) and a 3-minute escape from further demands (i.e., worksheets). As was typically occurring in the classroom, failure to meet criterion resulted in the end of the trial whereby staff redirected Liam to another task (i.e., short delay of or escape from demands and/or access to preferred tangibles).

Demand fading. After analyzing the results of the TBFA and baseline data, the team determined criteria for each level or "step" of a demand fading intervention for independent tasks by initially removing then gradually increasing the response requirement (e.g., # represents the number of tasks on worksheets) (e.g., Pace, Iwata, Cowdery, Andree, & McIntyre, 1993). For example, step 1 required Liam to write his name on the worksheet (Name), step 2 required Liam to write his name and complete 1 question on the worksheet (Name + 1), up to step # requiring Liam to write his name and complete # questions on the worksheet (NAME + #). During the intervention phase, the consultant or school staff conducted up to three, 10-minute sessions of several trials (mean = 12.2, range = 7–17) each week. Function-based consequences for meeting the target criterion step included access to tangible reinforcers (similar to baseline) and escape from further demands (3 minutes). Failure to meet criterion, resulted in the end of the trial and (a) a 3-second inter-trial interval or (b) the end of the daily session. After meeting the criterion across three consecutive trials, the target criterion was to increase to the next criterion step. After three consecutive demand fading trials in which the target criterion was not met, the target criterion was decreased to the previous step.

Generalization probes. Throughout the intervention and follow-up phases, the consultant or staff collected data during generalization probes which consisted of the consultant or a novel staff instructing Liam to complete novel, yet equally challenging tasks at the final criterion level (i.e., NAME + 5). Generalization probes were conducted approximately every 5 sessions to determine at which point in the intervention phase Liam may have acquired the skill at the final criterion level. As in baseline, no additional instructions, prompts, or reinforcement were provided.

Interobserver Agreement and Procedural Integrity

During the two TBFAs, two independent observers collected data on the occurrence of challenging behaviour during 70% and 82% of trials for the swearing and head banging TBFAs, respectively, with 95% and 97% interobserver agreement. During the intervention evaluation, two independent observers collected data on task completion during 15% of trials with 100% interobserver agreement.

Procedural integrity for the TBFA was determined similar to Austin et al. (2015) whereby observers recorded whether a correct or incorrect consequence (i.e., failed trial; error of commission or omission) was provided contingent on the target behaviour. Procedural integrity was calculated by dividing the number of correct trials (i.e., trials with the correct consequence) by the total number of trials (i.e., correct trials plus failed trials) and multiplying by 100 to generate a percentage. Procedural integrity was 91% and 96% for the swearing and head banging TBFAs, respectively.

Due to limitations imposed by some school boards and teachers' unions regarding staff evaluation, it may be difficult for a consultant to assess school staff behaviour, including procedural integrity, while maintaining professional boundaries. However, through collaboration, a procedural integrity checklist was created and formal procedural integrity was assessed by the consultant during 7.5% of intervention trials with 100% procedural integrity. Informal procedural integrity was assessed by school staff with weekly anecdotal reports of high procedural integrity.

Results

Data for two TBFAs are displayed in Figure 2 on the following page where the top panels display the percentage of trials in which Liam engaged in the target behaviour and the bottom panels display the latency to the target behaviour. Liam engaged in head banging most frequently during the test trials of escape from independent tasks (80.0% of trials), escape from social interaction (80.0% of trials), and access to tangibles (75.0% of trials). Visual analysis of the latencies to head banging helped identify variables that more significantly influenced behaviour. Short latencies (i.e., intervention team chose fewer than 20 seconds) to head banging occurred during 68.8% of escape from independent task test trials (triangles) with 81.9% of these occurring during challenging tasks or tasks requiring error correction (open triangles). Short latencies to head banging also occurred during 60.0% of tangible test trials and only 43.8% of escape from social interaction test trials. Liam engaged in swearing most frequently during the test trials of escape from independent tasks (80.0% of trials) and access to tangibles (70.0% of trials). Additionally, short latencies (i.e., fewer than 20 seconds) to swearing occurred during 56.2% of tangible test trials and 21.4% of escape from independent tasks test trials. Overall, analysis of the TBFA results indicated that both swearing and head banging were most sensitive to contingencies of escape from independent demands and access to tangible reinforcers (i.e., preferred items or activities).

Overall results of the demand fading intervention (see Figure 3 on page 63) indicate Liam gradually increased on-task behaviour in the absence of challenging behaviour and met the target criterion during 75.6% (25 of 33) of target trials. The generalization phase indicated that Liam engaged with the novel tasks with novel staff during 57.1% (8 of 14) of trials compared to a baseline of 0% of trials.

Discussion

Consistent with previous research (e.g., Austin, et al.; Lambert et al.) the results of the current study suggest the utility of conducting TBFAs on the development of function-based interventions in school settings. The use of the typ-

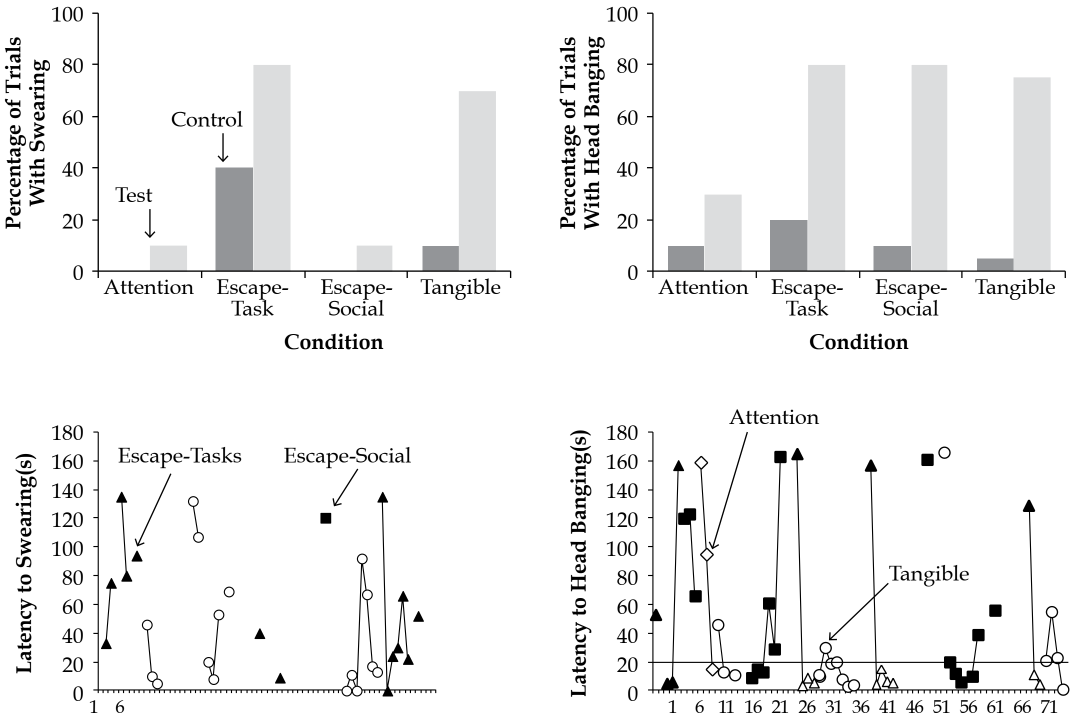

Figure 2. *Percentage of trials with challenging behaviour (upper panels) and latency to challenging behaviour (lower panels) during TBFA. In the top panels, the higher proportion of test trials (black bars)with challenging behaviour during escape and tangible conditions indicates that escape from demands and access to tangibles are maintaining variables. In the bottom panels, triangles indicate latency to challenging behaviour (i.e., how quickly Liam started to engage in the behaviour) during escape from task demand trials (closed triangles indicate mastered tasks, open triangles indicate challenging independent tasks), squares indicate latency to challenging behaviour during escape from social demand trials, diamonds indicate latency to challenging behaviour during attention trials, and circles indicate latency to challenging behaviour during tangible trials. Shorter latencies to challenging behaviour (i.e., datapoints below the criterion line) in the tangible (circle) and escape from independent demands (triangle) conditions indicate that the behaviour is particularly sensitive to these contingencies.*

ical summary results in addition to the latency results (e.g., Thomason-Sassi et al.) allowed the intervention team to determine that Liam's head banging and swearing were most sensitive to contingencies involving escape from challenging tasks as well as access to tangibles. The intervention team replicated and extended previous treatment evaluation research by using the results of the TBFAs to identify yet another function-based intervention (i.e., demand fading). This study also extended previous research by including generalization probes and a demonstration of experimental control through the use of a changing-criterion design. Additionally, by conducting the assessment in the same setting as the intervention and using materials and instructors from that setting, the ecological validity of the assessment results was enhanced. It is likely that the probability of the challenging behaviour contacting novel reinforcement contingencies is, therefore, minimized.

While the team collaboratively overcame barriers to assessing procedural integrity, the limited number of *formal* assessments is a limitation. Future research in schools should continue to examine ways of collaboratively and more thoroughly assessing procedural integrity of the TBFA (e.g., appropriate set up of discriminative stimuli, motivating operations, consequences) and interventions to convincingly demonstrate experimental control and identify support

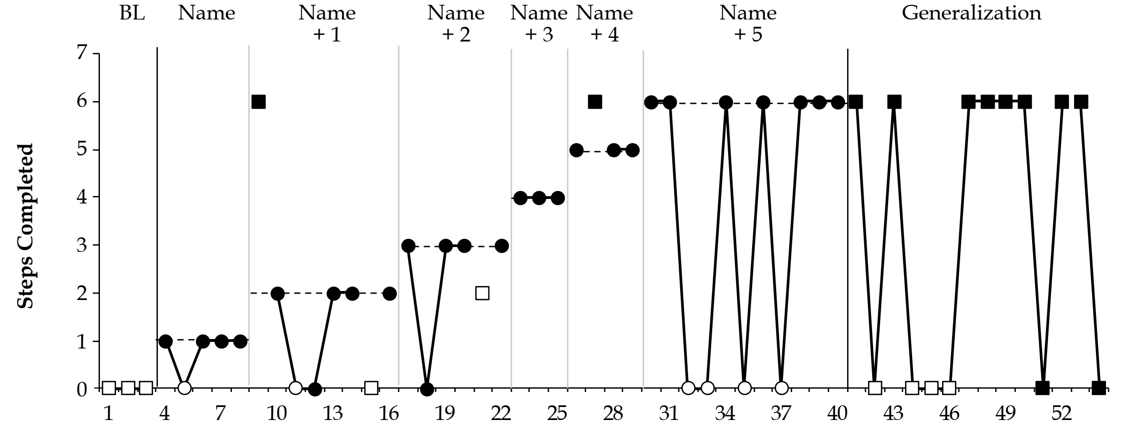

Figure 3. Criterion steps met across baseline, demand fading, and generalization phases. Squares indicate novel tasks, circles indicate training tasks. Open markers indicate presence of swearing and/or head banging. The broken horizontal line denotes the goal criterion in each phase. In the baseline phase, no identified task steps were completed. Throughout the demand fading intervention, responding gradually increased to match the increasing goal criterion – i.e., phase 1 (Name): write name; phase 2 (Name + 1): write name and compete 1 question; phase 3 (Name + 2): write name and complete 2 questions); up to phase 6 (Name + 5): write name and complete 5 questions, followed by phase 7 (generalization): write name and complete 2 questions using novel worksheets/with novel staff. In the final goal phase, and in later generalization probes, responding was variable but significantly improved from baseline levels.

needs (e.g., training, consultation). Another limitation is that some trials were conducted by a trained consultant instead of solely a classroom staff. Future research might examine school staff's implementation of effective, function-based interventions informed by TBFAs and the degree to which additional school staff training is required. Although a 20-second latency criterion was selected in the current study, future researchers should also consider examining the parameters for selecting a latency criteria when analyzing and interpreting FA data. The authors acknowledge that expanding the length of the test segment, in relation to the control segment, may increase the risk of a false positive response when conducting a lengthier test condition compared to the control condition. However, the success of the intervention suggests that the TBFA results are valid and future research is needed to assess the concordance between assessments utilizing equal versus unequal segments lengths.

Recent research has also highlighted the utility of conducting non-standard test conditions and additional analyses (e.g., synthesized) as well as identifying idiosyncratic and contextual variables that maintain specific behaviours (e.g., Hanley, Vanselow, & Hanratty, 2014; Lloyd et al., 2014). For example, research has suggested that many individuals with disabilities are highly sensitive to escape contingencies (i.e., social-negative reinforcement) with additional contingencies (e.g., social-positive) also contributing to multiple control (Asmus et al., 2004). The results of the two TBFAs and intervention evaluation conducted in the current study may provide additional evidence to support the findings of the influence of specific contingencies (e.g., escape from task demands, from error correction, from social demands), multiple contingencies (e.g., tangible as well as escape), and/or combined contingencies (e.g., escape-to-tangible). Future researchers may wish to examine the development of such escape-to-tangible-maintained challenging behaviours which may be influenced by previous instructional histories (e.g., during the course of discrete trial training in IBI, the child's behaviour is reinforced by "breaks" comprised of both escape from demands *and* access to tangibles).

Key Messages From This Article

People with disabilities. In schools, you deserve staff who take the time to understand your behaviour and teach you new, better ways to have your needs met.

Professionals. Through collaboration, functional analysis and function-based interventions can be powerful tools in all of the settings in which we support our clients, including schools.

Policymakers. Policies should promote the use of evidence-based best practices in assessment and intervention as they can effectively and safely be implemented in a school setting.

Acknowledgements

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ABSTRACTS FROM THE 2016 RSIG RESEARCH DAY LONDON ON, APRIL 8 – POSTERS

Acute and Long-Term Effects of Aerobic Exercise on Repetitive Behaviours and Task Performance for Adults With Autism Spectrum Disorder and an Intellectual Disability

Authors: Suzanne Ali, Chad A. Sutherland, Nadia Azar, Sean Horton
University of Windsor, Windsor ON
Correspondence: hortons@uwindsor.ca

Objectives

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is characterized by (1) deficits in social and communicative functioning, and (2) behaviours, interests and activities that are restricted and repetitive in nature. Thirty-one percent of individuals with ASD also have an intellectual disability (ID) and there is a negative correlation between IQ and the number of repetitive behaviours (RB) exhibited. These behaviours may interfere with an individual's ability to learn new tasks and/or perform familiar tasks. Exercise is an intervention that has been shown to reduce the number of RB exhibited by individuals with ASD. Moreover, exercising at a vigorous intensity may be needed to reduce the severity of RB. Thus, the purpose of this study is to determine whether individuals with ASD and ID (ASD-ID) will (1) exhibit fewer RB and for shorter durations immediately following a moderate-vigorous aerobic exercise session, (2) show an improvement in task performance immediately following each exercise session, and (3) exhibit a long-term reduction in the severity of the RB after engaging in a number of exercise sessions.

Methods

Case studies will be conducted with eight individuals with ASD-ID throughout an eight-week exercise program. Participants need to be at least 18 years of age, have a codiagnosis of ASD-ID, and exhibit a high number of repetitive behaviours (a minimum score of 2 is needed on at least one question from the stereotypic behaviour subscale in the Repetitive Behaviour Scale-Revised; RBS-R). Participants will engage in moderate-vigorous aerobic exercise on a stationary bike for 20 minutes, twice a week, for eight weeks. Exercise intensity will be tracked with the BODYMEDIA® armband. Before the start and after the completion of the program the participant's support worker, parent or guardian will complete the RBS-R. This scale will be used to assess any long-term changes in RB severity displayed by participants. Immediately before and after engaging in aerobic exercise participants will be video recorded for eight minutes, and perform a modified version of the Jebsen Hand Function Test (JHFT). Video observations will allow the researchers to assess any acute changes in the number and duration of RB exhibited. The modified JHFT involves six simple activities (i.e., turning over cards and stacking checkers) and will be used to determine if there is an improvement in task performance.

Results/Discussion

Data collection is expected to be completed by April 2016. It is hypothesized that there will be a reduction in the number and duration of RB immediately following each exercise session. Since RB interfere with an individual's ability to perform tasks, it is expected that a reduction in RB will translate into an improvement in task performance. Furthermore, it is hypothesized that participants will exhibit an improvement in the severity of RB over the eight-week intervention. Overall, this study may provide support for a nonpharmacological intervention for reducing repetitive behaviours, and improvements in task performance may aid future research on integrating adults with ASD-ID into independent living and/or employment settings.

Hypersensitivity Influences Specific Phobia and Insistence on Sameness in Children With but Not Without Autism

Authors: Karen R. Black,[1] Ryan A. Stevenson,[1] Busisiwe L. Ncube,[2] Magali Segers,[2] Sol Z. Sun,[1] James Bebko,[2] Aviva Philip-Muller,[1] Matthew Johnston,[3] Ze Yuan Wang,[1] Morgan D. Barense,[1] Susanne Ferber[1]

[1] University of Toronto, Toronto ON
[2] York University, Toronto ON
[3] Western University, London ON

Correspondence: krblack@yorku.ca

Objectives

Restricted interests and repetitive behaviours are defining features of autism spectrum disorder (ASD), yet understanding of the underlying mechanism of these symptoms remains limited. Two core behaviours, insistence on sameness (I/S), and hypersensitivity to sensory stimulation, have been linked with elevated measures of total anxiety and specific phobia subtypes in children with ASD. This novel investigation had two goals:

1. Determine the relationships between hypersensitivity, I/S, and specific phobia.
2. Compare these relationships between groups of ASD and typically developing (TD) children.

Methods

Parents of 92 children (ASD, $n = 46$, $M_{age} = 11.9$ years, $SD = 3.0$; TD, $n = 46$, $M_{age} = 10.9$ years, $SD = 3.1$) completed questionnaires reporting on their child's difficulties related to sensory processing (the Child Sensory Profile-2), I/S (the Repetitive Behaviour Questionnaire-2), and anxiety (the Spence Children's Anxiety Scale). A bootstrap mediation analysis was used to examine whether specific phobia was related to I/S because of its relationship with hypersensitivity.

Results

In the ASD group, our mediation analysis revealed a significant indirect pathway from specific phobia to I/S through hypersensitivity ($ab = 0.37$, $SE = 0.1$, 95% CI [0.17, 0.55]). Overall, specific phobia was related to I/S ($c = 0.48$, $SE = 0.13$, 95% CI [0.23, 0.73]); notably, the direct path accounting for the contribution of specific phobia to I/S, independent of hypersensitivity, was not significant ($c' = 0.19$, $SE = 0.10$, 95% CI [-0.05, 0.35]). Two additional models testing alternative directional pathways (hypersensitivity → specific phobia → I/S, and hypersensitivity → I/S → specific phobia) yielded non-significant mediation effects. All analyses were non-significant for typically developing children.

Discussion/Conclusions

Our findings indicate that hypersensitivity may play a mechanistic role in the relationship between specific phobia and I/S in children with ASD. Specifically, when a child with autism experiences distress from intense phobias, hypersensitivity to sensory stimulation appears to have a maladaptive purpose, intensifying the expression of restricted interests and compulsive behaviours. Importantly, this effect was only present for children in the clinical sample. This preliminary evidence suggests that future exploration of interventions that teach coping skills for children with ASD could be a key step towards reducing sensory reactivity and overall distress.

Emotion Regulation in Children With Autism Spectrum Disorder: The Role of Parent Co-Regulation and Scaffolding

Authors: Victoria Chan, Carly Albaum, Priscilla Burnham Riosa, Andrew Goodwin, Andrea Maughan, Jonathan A. Weiss

York University, Toronto ON

Correspondence: victing@yorku.ca

Objectives

Emotion regulation (ER), the set of processes that control emotions, may explain many of the externalizing (e.g., aggression) and internalizing (e.g., anxiety) emotional and behavioural problems in children with autism spectrum disorder (ASD). Parents can support children's emotional development and ER through co-regulation (i.e., motivational and emotional scaffolding, and helping their child regulate emotions), which may help improve psychopathology. However, research has only focused on very young children with ASD, despite parent support of child emotion regulation going well beyond the preschool years. The current study examines the following research questions:

What types of co-regulation strategies do parents of school-age children with ASD use?

What are the associations between parent co-regulation strategies, child ER, and child externalizing and internalizing problems?

Do child ER skills mediate the relation between parent co-regulation and child psychopathology?

Methods

All 49 participants (88% male, *N* = 43) were enrolled in a randomized controlled trial of CBT to improve ER in children with ASD, 8 to 12 years of age (*M* = 9.65, *SD* = 1.33) with average intellectual functioning (IQ > 80). Most parents in this sample were mothers (78%, *N* = 38). Data analyses are based on the baseline data collection period. We used two open-ended measures for child ER ability: *Dylan is Being Teased* and *James and the Math Test*. To measure parent co-regulation strategies, we applied a behavioural coding scheme to a standardized *Emotion Discussion Task*, in which each parent-child dyad discussed a time when the child felt anxious, angry, and happy (five minutes per emotion). We created three composite scores for parent co-regulation strategies: Vocal, Active, and Following. We also assigned global ratings for the quality of parent scaffolding using a 5-point Likert scale. Externalizing and internalizing problems were measured via the *Behavior Assessment System for Children, Second Edition – Parent Rating Scales*.

Results

The most commonly observed types of co-regulation strategies were prompting (*M* = 22.57, *SD* = 5.00) and emotion following (*M* = 21.63, *SD* = 5.30). Child externalizing problems were significantly associated with the mean quality of parent scaffolding ($r(46) = -.36$, $p = .01$) and child ER ability ($r(46) = -.31$, $p = .03$), and were marginally significant with the Following coregulation composite ($r(46) = -.28$, $p = .06$). The overall model accounted for 29% of the variance in externalizing problems, $F(4,40) = 4.11$, $p = .007$. Although child ER did not emerge as a significant mediator, parent scaffolding ($t = -2.12$, $p = .04$) and child ER ($t = -2.30$, $p = .03$) were significant independent predictors of externalizing problems.

Discussion/Conclusions

This is the first study to use observational methods to investigate parent co-regulation and ER in school-age children with ASD. Parents commonly used prompting and emotion following, which may help guide children's emotional experience and avoid emotional arousal, while helping children internalize adaptive ER skills. With future research, parent co-regulation and scaffolding may emerge as useful areas of focus in interventions targeting externalizing problems in children with ASD.

School Satisfaction in Parents of Canadian Children With Developmental Disabilities

Authors: Meisha Charles, Adrienne Perry, Jonathan A. Weiss
York University, Toronto ON
Correspondence: mkcharles@live.com

Objectives

School is a major part of the life of all children, including children with Developmental Disabilities (DD). Children with DD have the right to an "appropriate" education and may be in various types of educational placements. Parents of children with DD often experience difficulties and frustrations accessing appropriate services, including appropriate school programs (e.g., Zablotsky, Boswell, & Smith, 2012). However, surprisingly little research has been done on school satisfaction, especially in Canada.

The current study had three Objectives (1) to examine the overall level of school satisfaction in Canadian parents of children with severe/multiple DD compared to parents of children who are Typically Developing (TD); (2) to examine the validity and reliability of the GO4KIDDS School Satisfaction Scale; and (3) to describe nine specific aspects of school satisfaction (e.g., communication with school staff) in parents of children with severe/multiple DD, and investigate the relationship of school satisfaction to child, family, and environmental factors.

Methods

This study uses data from Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS), a CIHR-funded research program investigating the health, well-being, and social inclusion of school-aged children with severe/multiple DD across Canada. We first compared the overall school satisfaction between DD (n = 417) and TD (n = 210) groups, matched on key demographics. Children ranged in age from 4 to 19 and were 69% male. Respondents were primarily biological mothers (93% of DD, 94% of TD). The measure of school satisfaction was a single item rated on a 5-point Likert scale, ranging from *very dissatisfied* to *very satisfied*. We then used a subsample of 185 parents from the DD group, correlating a 9-item GO4KIDDS School Satisfaction measure with child (e.g., maladaptive behaviour), family (e.g., SES), and environmental (e.g., type of school placement) variables.

Results

Analyses are currently underway. Preliminary analyses show that the reliability of the GO4KIDDS School Satisfaction Scale is very good, with high internal consistency (✔ = .93) and item-total correlations (all over r = .62). Analyses will focus on the relationship of the total score on the scale to child, family, and environmental factors using Pearson r correlations and independent t-tests, and a subsequent hierarchical regression to determine the best predictors of school satisfaction.

Discussion/Conclusions

Preliminary findings suggest that the GO4KIDDS School Satisfaction Scale is a good measure, supporting its use to investigate the relationship of school satisfaction to child, family, and environmental factors. Despite the study's limitations as a correlational study, results are expected to have many implications for policy-making, training, planning, and advocacy.

Neuropsychological Differences in Attentional Biases and Distractor Responsiveness Between ADHD Adults and Their Peers

Authors: Jiaqing Chen,[1] Matthias Niemeier[1,2]

[1] University of Toronto, Toronto ON
[2] Centre for Vision Research, York University, Toronto ON

Correspondence: niemeier@utsc.utoronto.ca

Objectives

As a consequence of the right hemisphere dominance in visuospatial attention, neurologically healthy people have slight leftward attentional bias in visual perceptual tasks (i.e., pseudoneglect), and this bias is amplified by pixel noise as a result of distractor removal. Yet little is known about the underlying mechanisms of visuospatial attention in individuals with developmental challenges such as attention-deficit hyperactivity disorder (ADHD), and how they relate to their right brain dysfunction. The objective of the current study is to examine the pattern of attentional biases and pixel noise responsiveness in individuals with ADHD using a perceptual judgment task.

Methods

We asked 21 university students diagnosed with ADHD (*M* = 22.00, *SD* = 2.37) and 38 neurotypical controls (*M* = 19.56, *SD* = 2.12) to make perceptual judgments in a rating scales task (GST), which possesses good sensitivity and correlates reliably with other perceptual judgment tasks proven to capture attentional biases. We measured attentional biases and task sensitivities in adults with and without ADHD using the GST in a high (HI) and a low (LO) spatial-frequency condition of the GST, and we degraded stimuli with distracting pixel noise

Results

Consistent with our previous work, we found a "cross-over" effect of HI vs. LO biases (i.e., leftward bias in the HI condition and rightward bias in the LO condition) in the control group and the effect grew as a function of pixel noise. But the ADHD group exhibited no signs of pseudoneglect or noise-dependent amplifications. Interestingly, ADHD individuals produced psychometric functions with normal slopes, suggesting that they had little difficulty with the pixel noise. Furthermore, at intermediate levels of noise their biases became indistinguishable from neurotypical biases, suggesting a potential facilitatory effect of perceptual noise on performance for patients with ADHD.

Discussion/Conclusions

Our findings demonstrate that there is a severe lack of the right dominant normal attentional functions in ADHD that can be ameliorated with visual noise, perhaps through sensory stimulation. This study contributes to the growing literature of pathology of the right hemisphere in the ADHD population and increases our understanding of the neural mechanism of visuospatial abilities associated with attention deficit.

Making Space for Inclusive Research: Developing an "Easy Read" Text About Intimate Citizenship

Authors: Kimberlee Collins,[1] Kareem Elbard,[2] Rainbow Hunt,[2]
Ann Fudge Schormans,[3] Esther Ignagni[4]

[1] York University, Toronto ON
[2] Reimagining Parenting Possibilities Self Advocacy Group
[3] McMaster University, Hamilton ON
[4] Ryerson University, Toronto ON

Correspondence: kimberlee.collins@ryerson.ca

Purpose/Objectives

This presentation outlines the process of including self-advocates as co-researchers in an emerging line of international research collaboration, "Making Space for Intimate Citizenship." Despite considerable gains in promoting inclusive research with labelled people, there remain inequitable divisions in the labour of knowledge production. Key among these is the inclusion of labelled people in the theoretical, conceptualization and analytic stages of the research process. We focus on the specific process of creating "easy read" documents explaining intimate citizenship: "easy read" is an accessible, plain language document comprised of short sentences paired with explanatory images. We demonstrate how this facilitated access and inclusion of the co-researchers; challenged traditional research relationships; empowered advocates to be more involved in the research process; and enhanced the theorizing stage for everyone on the research team.

Methods

Two research teams comprised of self-advocate co-researchers, community partner organizations and academic researchers located in Ontario and Northern England engaged in a participatory arts-based dialogue to create accessible, "easy-read" web-documents. The process entailed iterative discussion, transcription and collaborative editing. Once a draft "easy read" document was completed, it was pilot tested with three different groups of labelled people. These groups were selected using convenience sampling techniques, each group consisted of four to seven participants. Groups provided verbal feedback to the co-researcher teams. Final edits were made to the easy read documents; documents were shared online for use in guiding an international connection workshop initiating the Making Space international research collaboration.

Results

Significantly, the project offered an unexpected opportunity for knowledge coproduction within mixed researcher teams. Through collaborative discussion and reflection, "intimate citizenship" was elaborated beyond current representations in traditional academic literature. Further, the concept was enhanced in a way that extended its application in research, service and advocacy. For instance, the project led to the development of a series of "easy read" documents explicating the elements of intimate citizenship. These included documents addressing citizenship, rights, intimacy, love, caring labour, consumer practices, neoliberalism and other research and advocacy related terms. The document was used to guide an ongoing international research initiative and enhance labelled people's engagement with the research process. However, it also revealed the extent to which Canadian self-advocates – in contrast to UK self-advocates – are marginal to the conceptualization and analytic stages of participatory research processes. Moreover, important differences between Canada and the UK regarding the visual/image representation within plain English texts were noted.

Discussion/Conclusions

Greater attention is needed to the challenges and possibilities of including labelled people in all aspects of the research process. The development and use of "easy read" documents is one way in which this can be facilitated. This has potential to enhance access and participation for *all* members of the research team.

IQOL: A Measure of the Impact of Problem Behaviour on Quality of Life

Authors: Rosemary Condillac, Meagan Scott

Centre for Applied Disability Studies, Brock University,
St. Catharines ON

Correspondence: rcondillac@brocku.ca

Introduction and Objectives

Community-based ABA programs for individuals with IDD/DD often use a "mediator-model" to treat challenging behaviours. In these programs a behaviour analyst develops intervention strategies and provides treatment plans to be implemented by natural caregivers (Gambrill, 2012). These government-funded programs have a common need for program evaluation measures that are (1) specific to ABA-based interventions, (2) go beyond numeric data to determine the degree to which observed changes in behaviour are meaningful to the individual and their caregivers, and (3) to determine the impact of behaviour changes on their life quality. Condillac (2009) has designed a system of program evaluation measures to meet the preceding needs. These measures are designed to (1) track ABA assessment and intervention techniques and behavioural outcomes, (2) measure the perceived severity of problem behaviour by caregivers, and (3) determine the impact of problem behaviour on the quality of life of the individual and those in their environment. This poster will focus on the development of the Impact on Quality of Life Scale (IQOL; Condillac, 2009), which measures the degree to which the problem adversely impacts the individual's quality of life and that of others in their environment.

Methods

For this poster, the measure was piloted with the caregivers of 25 individuals with ASD/DD who were receiving community based ABA treatment for problem behaviour. Behaviour consultants working with the parents administered the measure. The reliability, face validity, and usability of this measure were examined.

Results

Preliminary results from the 25 caregivers suggest that the IQOL is user friendly, focuses on areas of quality of life that are impacted by problem behaviour, and has acceptable internal consistency (.871 for individual, .950 for caregiver, and .949 for the full scale).

Discussion/Conclusions

These results provide support for further research and field-testing of the IQOL within a prospective program evaluation pilot.

Exploring the Development of Independence, Sexuality, and Social Relationships Among Adults With Intellectual Disability in London, Ontario

Authors: Vanessa Cox, Treena Orchard, Anne Kinsella, Pamela Cushing
Western University, London ON
Correspondence: pcushin@uwo.ca

Objectives

Transitioning to adulthood for individuals with intellectual disabilities (ID) can be fraught with unique challenges as compared to their counterparts without. One aspect of transitioning to adult status that is often overlooked for adults with ID is the formation and maintenance of meaningful platonic and sexual relationships. The proposed research will explore how adults with ID exercise independence in the development and negotiation of socio-sexual relationships, namely friendships and intimate partnerships. The following questions have been designed to achieve this research aim: (1) What role does the issue of independence play in the development of socio-sexual relationships among adults with intellectual disability? (2) To what (if any) extent do caregivers and others in the social/care environment facilitate and/or create barriers in the development of these socio-sexual relationships? (3) How do these experiences with and potential challenges related to relationship formation affect the social and sexual health of adults with intellectual disability?

Methods

The methodology of the proposed research will be qualitative, a form of inquiry that focuses on gaining an in-depth understanding of the experiences and perspectives of the social world in which each participant resides. 20 adults with ID (aged 19 and above) residing in London, Ontario will be recruited from various supportive agencies, such as Community Living London, and the London Down Syndrome Association. Each participant will engage in a one-hour semi-structured interview during which time the primary researcher will explore the experiences they have had regarding relationship formation according to the research questions stated in the objective. Additionally, five parents and five support workers will be interviewed in order to investigate the experiences and attitudes they hold in regards to supporting the formation of relationships by the adults they support. This will be done in order to provide triangulated data, which enriches the quality of qualitative data analysis.

Results

Data collection of the proposed study is expected to begin in March of 2016.

Discussion/Conclusions

Organizational, National, and International policies stress the importance of valuing the rights of people with ID as equal to those without, and this includes matters related to the formation and maintenance of meaningful relationships. It is currently unclear as to how (or if) these policies that stress the importance of supporting the formation of meaningful relationships are enacted at the individual level. The proposed study will address this knowledge gap by presenting the experiences adults with ID in London, Ontario have had in this realm. The real-world experiences gained from this research may be used to inform policies and handbooks to better enable supporters and caregivers of adults with ID to encourage the formation independent, healthy, and meaningful relationships.

Co-Occurring Problems in Auditory Filtering and Intersensory Processing of Speech Information in Children With Autism Spectrum Disorder

Authors: Hadas Dahary, Lisa N. Alli, James M. Bebko
York University, Toronto ON
Correspondence: hadas.dahary@mail.mcgill.ca

Objectives

Children with autism spectrum disorder (ASD) experience abnormalities in sensory processing compared to typically developing peers. Some abnormalities in sensory perception include a difficulty to integrate input from multiple sensory modalities (Iarocci & McDonald 2006). This difficulty is particularly evident when processing linguistic information, which suggests that language is closely associated with intersensory processing abilities in ASD (Bebko, Demark, Weis, & Gomez, 2006).

Auditory filtering is the ability to filter out salient sound from background noise, such as when "tuning in" to a conversation in a noisy social environment (the cocktail party phenomenon). Auditory filtering impairments have been found in ASD (e.g., Rogers, Hepburn, & Wehner, 2003). This impairment may be related to the speech-specific deficit in intersensory processing observed in individuals with ASD as both processes require individuals to selectively pull out language-related information in complex social settings. We investigated whether or not auditory filtering abilities described by parents can predict observed intersensory processing of speech.

Methods

Participants included 18 children with ASD and a matched group of 20 children with typical development, six to 16 years old. Parents completed the Short Sensory Profile Questionnaire and children viewed a screen displaying identical videos in each of the four quadrants of the screen. The videos were offset in time from one another with the auditory track synchronized to only one of the screens. Some of the videos contained linguistic information (a woman telling a story) and some contained non-linguistic information (e.g., a finger pressing on piano keys). An eye-tracking device recorded the participants' eye movements.

Results

Parent-reported Auditory Filtering scores (from the Short Sensory Profile) significantly predicted the proportion of time looking within the synchronous screen for the ASD group, $r(16) = .6$, $p = .009$, but not for the TD group. However; this relationship was only apparent for the linguistic stimuli. Auditory Filtering was not correlated to looking time to the non-linguistic stimuli for either the ASD or TD groups.

Discussion/Conclusions

Auditory Filtering seems to be closely associated with intersensory perception in children with ASD and, perhaps exclusively, with the intersensory processing of speech. To better understand if deficits in Auditory Filtering play a key role in difficulties in intersensory perception of speech, a more longitudinal study would be beneficial, or a measure with a more finely categorized degree of auditory filtering may be helpful. Early remediation of auditory filtering challenges may promote the development of socio-linguistic communication.

On the Effectiveness of Teaching Memory Strategies: A Japanese-Canadian Cross-Cultural Examination of Training in Clinical and Non-Clinical Samples of Children

Authors: Hadas Dahary,[1] Yuki Konomi,[2] James M. Bebko[1]

[1] York University, Toronto ON
[2] Durham Psychologists, Ajax ON

Correspondence: hadas.dahary@mail.mcgill.ca

Objectives

Children with typical development use spontaneous cumulative rehearsal strategies in memory tasks by approximately 7 years of age (e.g., Bebko, 1979, 1984), In contrast, many children with developmental difficulties, such as children with autism spectrum disorder (ASD), are less active strategy users. Nonetheless, rehearsal has been linked to proficient language skills in both ASD and non-ASD groups (Bebko & McKinnon, 1990; Bebko & Ricciuti, 2000, Bebko et al., 2015). However, since most of the rehearsal studies have been conducted in a Western cultural context and are embedded in the English language it is unclear whether this relationship is in fact universal outside the Western socio-linguistic culture. Furthermore, although there is research indicating positive effects of rehearsal training in several developmentally challenged populations, such as Down syndrome (Broadly & MacDonald, 1993), researchers have not extensively investigated the effect of rehearsal training in children with ASD. To address these questions, the current study examines the emergence of rehearsal use crossculturally in a non-Western context and evaluates the immediate and long-term effectiveness of rehearsal strategy training in children with ASD in Japan and Canada.

Methods

Samples of 4- to 8-year-old non-clinical children and children with ASD in Japan and in Canada were tested in a multiple-baseline design, where each child acts as her/his own control. During serial recall tasks, rates of spontaneous rehearsal use were determined for all groups and the effectiveness of a one-session strategy training procedure was assessed.

Results

Results for the Japanese samples essentially paralleled the Canadian samples. Few spontaneous rehearsal strategy users were found in either ASD group. In addition, across both clinical and non-clinical samples in both countries, rehearsal use was associated with verbal mental age of the child, providing indirect support for the language proficiency – rehearsal use relation across languages and cultures. The strategy training session was initially effective; however, two weeks after training, strategy use was not well-maintained nor generalized, particularly for the ASD groups.

Discussion/Conclusions

Findings from the current study demonstrate that (1) the hypothesized relationship between language skills and rehearsal use seems largely culture, language and diagnosis-free, with a similar pattern of emerging memory strategy use in the two language groups, and (2) a one-session strategy training was initially effective; however, it appears that the length of training needs to be extended for children with ASD to maintain and generalize gains. Please note: This submission is one of three related presentations/posters submitted together from our lab.

"In Medical School, You Get Far More Training on Medical Stuff Than Developmental Stuff": Perspectives on ASD From Ontario Medical Practitioners

Authors: Golnaz Ghaderi, Shelley L. Watson
Laurentian University, Sudbury ON
Correspondence: gghaderi@laurentian.ca

Objectives

Individuals with autism spectrum disorder (ASD) demonstrate a wide range of impairments in communication and social function, as well as repetitive behaviours and restricted interests (Devlin & Scherer, 2012). According to the Centers for Disease Control and Prevention (2014), approximately, 1 in 68 children is diagnosed with ASD. Parents of children with ASD have raised concerns regarding the delay in diagnosis of ASD (Keenan et al., 2010), medical practitioners' lack of knowledge about diagnosis and treatment of ASD (Carbone et al., 2010), and lack of social support due to the paucity of financial and medical resources (Glazzard & Overall, 2012). Health care professionals play an important role in identification and treatment of children with ASD. Nonetheless, research shows that although children with ASD often show signs of autism as early as six months of age, they do not receive a diagnosis until the age of 3–4 years (Rhoades, Scarpa, & Salley, 2007). As Rhoades and colleagues (2007) stated, many health care providers feel incompetent in both the assessment and diagnosis of ASD. For example, research suggests that many medical practitioners in the United States have raised their concerns about how demanding the ASD screening tools are with regards to knowledge, time and administration (Carbone et al., 2010; Nah, Young, Brewer, & Berlingeri, 2014). Nonetheless, there is a paucity of research on these matters in Ontario. Therefore, the purpose of this research is to investigate the knowledge of Ontario medical practitioners regarding the diagnosis and treatment of ASD in Ontario.

Methods

A total of 26 medical practitioners including family physicians, paediatricians, developmental paediatricians, psychiatrists and emergency doctors were recruited from Northern Ontario, Ottawa region, Niagara Falls, and Toronto. My research employed a two-phase, mixed methods approach. During the first phase, participants filled out a questionnaire regarding their knowledge and attitudes about ASD. The second phase incorporated a semi-structured interview, in which participants were asked to answer questions with regard to their knowledge about the identification, diagnosis, and treatment of ASD. The participants were also asked about their experiences of working with this population.

Results

Data collection is ongoing, but preliminary analysis of the quantitative results, using descriptive analysis, Paired samples *t*-tests and correlations, revealed that there is a significantly higher perceived level of knowledge regarding the assessment and treatment of ASD in comparison to other developmental disabilities such as fragile X syndrome and fetal alcohol spectrum disorders. The results also showed that there is a significant positive correlation between participants' perceived levels of knowledge regarding the diagnosis and treatment of ASD and their previous work or volunteer experiences with individuals with ASD. Nonetheless, no significant correlation was found between the years of practice and perceived level of knowledge regarding the diagnosis and treatment of ASD. The results of the interview also showed that there is a discrepancy between participants' perceived levels of knowledge regarding the diagnosis and treatment of ASD and their reported comfort level dealing with these patients. In addition, the analysis of the interviews indicated that the participants diffuse responsibilities to other medical practitioners with regard to diagnosing and treating individuals with ASD.

Discussion/Conclusions

The results of this study will provide a better understanding of medical practitioners' knowledge with regards to the diagnosis and treatment of ASD. Findings will also have implications for raising awareness in health care systems regarding the steps that need to be taken in order to enhance the diagnosis and treatment of ASD.

Effects of the Adapted Peers© Program on Adults With Developmental Disabilities and Challenging Behaviour

Authors: Brenda Greaves, Liz Graham
Bethesda Services, Thorold ON
Correspondence: bgreaves@bethesdaservices.com *or* lgraham@bethesdaservices.com

Objectives

The Program for the Evaluation and Enrichment of Relational Skills (PEERS) is a parent-assisted intervention focusing on teens in high school that are having difficulty making or keeping friends. This program has been evaluated and found to be effective amongst its target population of teens with Asperger's and high functioning autism. To the best of our knowledge, there is little evidence on the generalizability of the program to different populations. This study examines whether specific accommodations could be applied to the PEERS program in order to replicate the PEERS' ASD findings with adults who have intellectual disabilities and developmental disabilities (IDD), and who engage in frequent challenging behaviours (CB) and live in a residential setting.

Methods

Bethesda Services is a not-for-profit organization that provides clinical services and residential placement for adults with IDD, including those with CB. In this study seven adults that resided in a highly-staffed residential setting voluntarily attended a modified version of the PEERS program. The modifications were made with permission of the authors of the PEERS program, and included omitting the lessons that were believed to be of more complex content, providing the participants with frequent breaks and additional opportunities to role play, and creating supplementary resources such as visuals of the core concepts, "cheat sheet" of the skills taught and homework pages. The group ran once a week for 2 hours for duration of 8 weeks. Instead of the parent group, direct support professionals attended a staff only group, which ran concurrently for 1.5 hours for duration of 9 weeks. Both the adult and the staff sessions where video recorded assess internal validity of the curriculum.

Results

Evaluation was completed by using a pre- and post-test measure recommended through the PEERS curriculum – Total Assessment of Social Skills Knowledge (TASSK). In addition to this measure, *in-vivo* behaviour probes were completed pre- mid- and post-test, and approximately 3 months following the post-test. The results of the pre- and post-test TASSK scores showed a significant increase ($p = .01$) in the social skills knowledge of the participants; observational probes also showed improvements.

Discussion/Conclusions

The poster will elaborate on the specific accommodations made to the curriculum, results and efforts made to maintain treatment integrity. We will examine the limitations of this study and future research.

Follow-Up Assessment of an Evaluation of Behavioural Skills Training for Teaching Graduate Student Therapists to Provide Evidence-Based Treatment to Children With Autism Spectrum Disorder

Authors: Mahfuz Hassan,[1] Kendra Thomson,[1] Maria Khan,[2]
Priscilla Burnham Riosa,[2] Jonathan A. Weiss[2]

[1] Brock University, St. Catharines ON
[2] York University, Toronto ON

Correspondence: kthomson@brocku.ca

Objectives

There is a strong literature base to support the effectiveness of evidence-based practice (EBP) for youth with autism spectrum disorder (ASD). However, there is a dearth of knowledge regarding best practices for training therapists how to implement EBP. Ensuring therapists are well trained to implement best practices is vital to outcomes for individuals with ASD. The current study assessed the effectiveness of a passive training strategy (self-study of intervention manuals) versus an active training strategy (Behavioural Skills Training, BST) for therapist skill development. We are currently assessing maintenance of skills over time and generalization of skills from training contexts to practice.

Methods

We conducted a modified multiple-baseline design across three pairs (n = 6) of graduate student therapists recruited to implement a manualized emotion regulation intervention for youth with ASD. Therapists first completed 3 hours of passive training (self-study of manuals) followed by 3 hours of active learning (Behavioural Skills Training, BST). After each phase, we assessed therapists' performance in mock sessions with a confederate role-playing a child with ASD. Trained observers then coded therapists' performance in each phase on two outcome measures: (1) session fidelity, scored as percent correct on session checklists (interobserver agreement M = 95.76%, range = 86.67%–100%); and (2) session quality, rated on a 5-point Likert scale (interrater reliability M = .92, range = .84–.99).

Results

Five of the six therapists demonstrated an increase in fidelity after active training (M = 4.76%, change from baseline, range = -1.57%–8.77%), and four of the six therapists showed an improvement in session quality (M = 0.30, change range = -0.20–1.28). Observers are currently coding therapists' performance in follow-up sessions with children with ASD to assess for generalization and maintenance of session skills and quality, as well as if therapist performance in training is predictive of performance in the therapeutic context.

Discussion/Conclusions

After active training (BST) therapists demonstrated improved implementation behaviour as measured by fidelity checklists and improved session quality ratings compared to their scores after the passive training (self-study). Empirical support for active training strategies may lead to enhanced training for important individuals who provide essential services to individuals with ASD, and in turn better outcomes for clients.

Raising an Adolescent With Autism Spectrum Disorder: A Qualitative Study

Authors: Hilda Ho, Adrienne Perry
York University, Toronto ON
Correspondence: hildaho@yorku.ca

Objectives

Although autism spectrum disorder (ASD) is a lifelong disorder, much of the current literature has been focused on the experiences of families with young children. As the child matures, the research becomes sparser and the experiences, needs, and outcomes of individuals and their families during the period of adolescence and adulthood have remained largely unexamined. The limited number of studies on this population suggest that adolescence is a challenging and resource-intensive time for families. In this poster, we will describe the lived experiences of parents raising an adolescent with ASD. Specifically, we will identify the needs of adolescents and their families and document areas of strength.

Methods

This study was conducted as part of a larger study following the outcomes of adolescents who previously received early intervention. The adolescent participants in this sample were 14 to 20 years old and were being assessed on their cognitive ability, adaptive behaviour, academic skills, autism symptom severity, and social-emotional functioning. Semistructured in-depth interviews ranging from 1 to 1.5 hours long were conducted with 10 families with adolescents diagnosed with ASD and variable cognitive ability. Grounded theory was used to analyze the parents' perspectives and feelings about the meaning of ASD, current experience with raising an adolescent with ASD, changes from childhood to adolescence, and expectations for the future.

Results

In our sample, preliminary qualitative analyses revealed that, over the years, the meaning of ASD for these parents became more multi-faceted as they learned to better understand their child. Parents reported feeling more positive about the diagnosis and discussed the improvements their child has made since the first diagnosis. The majority of parents responded that they were satisfied with the treatments and services that were offered in early childhood but some felt that the current services offered do not meet their adolescent's needs. Parents also reported struggling with their adolescent's growing need for independence and how to best support him/her.

Discussion/Conclusions

Many parents reported more positive experiences from childhood to adolescence. Parents found that they felt more empowered and confident with their knowledge of ASD to better advocate for their adolescent. Findings from preliminary qualitative analyses suggest that a service gap exists for adolescents with ASD. More emphasis is needed on providing better supports for transitioning into high school and services which address the comorbid mental health disorders with ASD.

Predictors of Frequent Emergency Department Visits in Young Adults With Developmental Disabilities

Authors: Barry Isaacs,[1] Jonathan A. Weiss,[2] Andrew Wilton,[3] Heidi Diepstra,[1] Yona Lunsky[4]

[1] Surrey Place Centre, Toronto ON
[2] Department of Psychology, York University, Toronto ON
[3] Institute for Clinical Evaluative Sciences, Toronto ON
[4] Centre for Addiction and Mental Health, Toronto ON

Correspondence: barry.isaacs@SurreyPlace.on.ca

Objectives

This study aimed to identify: (1) the percentage of young adults with developmental disabilities (DD) age 18–24 in Ontario, who visit the emergency department (ED) frequently, and (2) factors that determine the frequency of ED visits in this population.

Methods

A sample of 15,980 young adults with DD was derived from a larger cohort of 66,484 individuals with developmental disabilities ages 18–64 in Ontario, constructed previously by linking Ontario administrative health data held at the Institute for Clinical Evaluative Sciences and social supports data held by the Ontario Ministry of Community and Social Services. The current study compared young adults with DD who visited the ED five or more times in the fiscal year 2009/2010, with those who visited the ED zero to four times in the fiscal year 2009/2010. A multivariate logistic regression was performed to predict high frequency of ED visits in young adults with DD from demographics (age, sex, income, area of residence), health characteristics (presence of autism spectrum disorder (ASD), psychiatric disorder, addiction, morbidity), and health services use (primary care visits, psychiatrist and specialist visits, ED visits, hospital admission, continuity of care).

Results

Of the 15,980 young adults with DD, 4% visited the ED at least five times in a one-year period ($n = 626$). The group of frequent ED visitors was more likely to be female, live in low income neighbourhoods, have a psychiatric disorder or substance addiction, have greater overall ill-health, and have greater degree of health service use but lower continuity of care than those who accessed the ED less than five times. The group of frequent ED visitors were also less likely to have a diagnosis of an ASD, and come from large urban centres than other young adults with DD.

Discussion/Conclusions

Demographic, health/mental health status and service use factors all contribute to frequent ED use in young adults with DD. Future research might focus on better meeting the need of individuals with poorer health and/or mental health in the community. In addition, the relationship between ASD diagnosis and ED use requires further exploration. Finally, continuity of care is one area of intervention that could be explored to address the needs of young adults with DD who use the ED frequently.

Perceptions of Family Quality of Life for Parents Raising Children With Autism

Authors: Jenna B. Jones, Marcia N. Gragg
University of Winsdor, Windsor ON
Correspondence: jonesjb@uwindsor.ca

Objectives

There has been considerable research focusing on the quality of life of individuals with developmental disabilities, but recently there has been a shift towards considering the quality of life of all family members (Samuel, Rillotta, & Brown, 2012). Family Quality of Life (FQOL) includes domains such as physical and material well-being, emotional well-being, family interaction, parenting, and disability-related support (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Little research has examined FQOL specifically for parents of children with autism. The purpose of the present study was to develop an understanding of how parents of children with autism perceive FQOL and an accompanying measure (Hoffman, et al., 2006). In addition, the results have been used to develop the methodology for a doctoral dissertation.

Methods

Eleven parents of children with autism (nine mothers, two fathers) were recruited for this study through a preschool for children with autism. Participants completed a demographic questionnaire and the Beach Centre Family Quality of Life Scale (FQOLS; Hoffman et al., 2006), which has 25 items that are rated on a scale from 1 (*Very Dissatisfied*) to 5 (*Very Satisfied*). Parents met with the first author and provided feedback about this questionnaire and answered interview questions about their experiences as parents of children with autism and how this relates to their FQOL. Interviews were transcribed and coded by trained research assistants. Transcripts were then analyzed using Braun and Clarke's (2006) Thematic Analysis by the authors, a psychology graduate student, and the parent advisor for the project.

Results

Due to the small sample size, the ratings of the FQOLS are described and no statistical tests were conducted. Participants in this study had an average total score of 104 on the FQOLS, which indicates a relatively high level of satisfaction with FQOL (scores potentially range from 25 to 125). Participants generally indicated that the FQOLS was easy to fill out and relevant to their experiences. Participants described how their lives are "different" and "difficult," but that their experiences have also allowed for "growth." The importance of "resources" and "support" was emphasized, along with the benefits of focusing on "family interaction." An unexpected theme was the experience of unsupportive social responses (mentioned by six of 11 participants).

Discussion/Conclusions

The results of this research will give researchers and practitioners a richer understanding of how parents perceive FQOL and this accompanying measure. The parents' responses highlighted the ways in which raising children with autism impacts the entire family unit and their quality of life. This study represents a first step towards applying the FQOL body of research to parents of children with autism. An area of further interest is the nature of unsupportive social responses in relation to FQOL in this population. There is often an assumption that all interactions with others are beneficial, but this research suggests that unsupportive responses are a common experience for parents of children with autism. The present study is limited by its small sample size, which will be addressed in future research related to this project.

Self-Directed Learning for Interview Skills

Author: Kelly Kerr
Kerry's Place Autism Services, Central East Region, Aurora ON
Correspondence: kelly.kerr@kerrysplace.org

Objectives

Individuals with developmental disabilities are less likely to obtain employment that is equal to their acquired education. Employment rates for individuals diagnosed with Asperger syndrome range between 5%–55% (Kreiger, Kinebanian, Prodinger & Heigl, 2012). Providing skills to improve interview skills may be beneficial in obtaining a desired position. The current single subject study followed a 15-year-old boy, diagnosed with Asperger syndrome in his socially significant, self-selected goal of improving his interview skills.

Methods

The participant used worksheets and reviewed corresponding video models for target questions. After review of worksheets and video models, a Behaviour Skills Training (BST) approach was utilized to teach the target questions. The participant was to review worksheets and video models at home, and practice with his parents. Once all target questions had been reviewed, the participant engaged in weekly mock interviews. He was also provided a list of the questions, but was unaware of the order which they would be presented. Generalization was built into the program where each week the meeting space changed and the primary interviewer changed.

IOA data was collected for 100% of treatment sessions (not collected for baseline) and ranged between 74.2%–100% accuracy. The mean IOA was 89.9%. The parent was able to collect consistent data that was comparable to that of the autism consultant.

Results

The participant progressed throughout the program and by the last session exceeded the expectations for appropriate responding for all 11 target interview questions. Generalization was built into the program where each week the meeting space changed and the primary interviewer changed to ensure that the participant could apply these skills in a variety of interviews, with unfamiliar adults in unfamiliar settings.

Discussion/Conclusions

Utilizing a treatment package which included BST, worksheets + video modeling, and mock interviews resulted in a successful outcome for the participant.

A limitation of this study is that it is unclear if one aspect of the treatment package produced the obtained results, making the other aspects redundant or if the combination of the different aspects together produced the results. Future research should look into each aspect individually, in regards to interview training for teens with Asperger's.

Another limitation was that this study did not address other interview skills such as body language or behaviours which may be a hindrance during interviews such as mumbling, stereotypy, eye contact, etc. Future studies may wish to include training body language on non-verbal cues.

Psychosocial Outcomes in Adoescents With Autism Who Received Intensive Behavioural Intervention as Young Children

Authors: Julie Koudys,[1] Adrienne Perry,[2] Hilda Ho,[2] Meisha Charles[2]

[1] Brock University, St. Catharines ON
[2] York University, Toronto ON

Correspondence: julie.koudys@brocku.ca

Objectives

Intensive Behavioural Intervention (IBI) has been shown to result in increased cognitive and adaptive skills in many efficacy studies (e.g., Lovaas, 1987), as well as in community effectiveness studies in Ontario (Freeman & Perry, 2010; Flanagan, Perry, & Freeman, 2012; Perry et al., 2008). However, clinical wisdom suggests that even children with "best outcomes" (e.g., average IQ) may struggle in social situations and may experience emotional difficulties, especially anxiety. Long-term follow-up studies of children who received IBI in their early years are very rare and have focused on IQ, adaptive skills, language, and school placement as outcome variables. Social-emotional-behavioural status has rarely been assessed, although children from the original Lovaas cohort were reported to show no socialemotional difficulties 5 years after treatment (McEachin, Smith, & Lovaas, 1993). Research on "optimal outcome" children with autism (independent of the IBI literature), also suggests some children with autism subsequently function in the normal range on various measures including social-emotional-behavioural ones (Kelley, Nagles, & Fein, 2009), and these children are more likely to have received IBI compared to a group with "high functioning autism." The purpose of this study was to conduct a thorough assessment of the social-emotional-behavioural functioning of a small group of adolescents who received IBI as young children in Ontario, as part of a larger follow-up study. We were interested in the presence of clinically significant difficulty (scores in the Clinical or Borderline range) in various psychosocial domains and the degree of consistency across respondents (parents, teachers, youth).

Methods

The sample includes about 13–15 youth (current age 14–17 years) who had received IBI when they were roughly 3 to 5 years old and who had good outcomes (improvements on cognitive, adaptive, and autism severity measures) in a previous short-term follow-up study (Prichard & Perry, 2010). Three measures were used from the Achenbach System of Empirically-Based Assessment (Achenbach & Rescorla, 2001), which is a well-established approach to measuring social-emotional-behavioural problems in children and youth, along the broad dimensions of Internalizing (e.g., anxiety, depression) and Externalizing (e.g., aggressive, hyperactivity, noncompliant) disorders. These were: the Child Behavior Checklist (CBCL; parent report), the Teacher Rating Form (TRF); and the Youth Self-Report (YSR) for adolescents aged 11–18 years who were able to complete it.

Results

Data are being coded and analysed currently. The majority of the sample analyzed todate were rated as having no scores in the Clinical range. Only three of 13 cases examined so far obtained scores in the Clinical range for Anxiety/Depression or Withdrawn/Depressed. Ratings were generally consistent across the three respondents.

Discussion/Conclusions

Results, to date, suggest that at least some children with autism who receive early IBI and respond well, go on to demonstrate social-emotional-behavioural profiles that are in the average range.

Exploring the Impact of Enhancing Social Media Skills on Experiences of Social Inclusion Among Youth With and Without Disabilities

Authors: Jennifer Leo,[1] Hilde Zitzelsberger,[2] Alexandra Zidenberg,[3] Cathleen Edwards[1]

[1] Abilities Centre, Whitby, ON
[2] University of Ontario Institute of Technology, Oshawa ON
[3] Laurentian University, Sudbury ON

Correspondence: jleo@abilitiescentre.org

Objectives

Inclusion has been defined as the belief that everyone is equally welcomed as a member of a community (Siperstein, Parker, Norins Bardon, & Widaman, 2007; Whitehurst & Howells, 2006). Despite the importance of friendship and its impact on quality of life, youth with disabilities do not experience the same degree of social inclusion as their peers without disabilities. Many youth with disabilities have fewer friends, experience more difficulty in socializing with peers, and face barriers (e.g., physical inaccessibility, negative social attitudes) that impact their participation in communities (Soderstrom, 2009; Shakespeare, 2006). Also, as this age cohort prepares to transition from the formal educational system, they begin to look for opportunities to participate within their communities and develop new friendships. Little is known about how social media may enhance their social participation and inclusion. The purpose of this study was to explore the impact of a social media skills program on experiences of social inclusion among youth with and without disabilities. Specifically, this study addressed the following research questions: (1) What does social inclusion mean to youth with and without disabilities? (2) How does the use of and access to social media tools impact social inclusion for youth with and without disabilities? (3) What are the potential benefits and challenges to using social media tools for youth with and without disabilities?

Methods

A qualitative case study was used to explore the perspectives about social inclusion and the development of social media skills among youth with and without disabilities.

Participants completed a survey at three points in the study, prior to the beginning of the social media program, at the end of the social media program, and 2 months following completion of the program. The 20 participants (n = 11 male, n = 8 female) ranged in age from 12 to 24 years, and included 15 individuals with various physical and/or developmental disabilities and five individuals without disabilities.

Results

Preliminary findings suggest that most participants with and without disabilities routinely use and value the use of social media for social interactions, especially with friends. However, they did not increase their use of social media tools upon completion of the social media program. Yet, participants revealed an increased understanding of safety concerns associated with social media use and described how they social media is an crucial means by which to stay connected with friends and family, especially those they do not see in person on a regular basis.

Discussion/Conclusions

Participants revealed a more critical and reflective approach to their social media use, which suggests that the inclusive program may have prepared them to engage in more positive social behaviours. Although the findings do not specifically indicate increased friendships, it is possible that by becoming more experienced in their use of social media tools, the youth with disabilities may become less socially isolated. Further study is needed to explore the long term impact of a social media program and follow the youth as they continue to mature.

Informational Support for Women With Intellectual and Developmental Disabilities During Pregnancy: A Qualitative Study

Authors: Rebecca Lindenbach,[1] Lynne Potvin,[1] Hilary Brown,[2] Virginie Cobigo[1]

[1] University of Ottawa, Ottawa ON
[2] Women's College Research Institute, Toronto ON

Correspondence: vcobigo@uottawa.ca

Objectives

Women with intellectual and developmental disabilities (IDD) are a high-risk population during pregnancy and childbirth, yet there are fewer accessible resources available for this population. Where resources do exist, there is a lack of research on their effectiveness from the perspectives of the women receiving the services; this study aims to start discussion among the research community on this topic. This study's objectives are to describe the knowledge women with intellectual and developmental disabilities (IDD) have concerning pregnancy and childbirth, sources of informational support, and barriers and facilitators to obtaining informational support.

Methods

This was a qualitative study that used a descriptive case study framework. Data for this study originated from a larger project on social support for women with IDD during pregnancy. The participants for the current study were two women with IDD who were residing in Ontario, were 18 years or older, and had given birth at least once in the five years prior to the interview. Data were collected using semi-structured interviews that included demographic information, a social circles task, and an adaption of the Social Support Self-Report (SSSR). A content analysis framework was used to analyze the interview data. Data were coded and organized into matrices for each participant based on the study objectives.

Results

One participant actively pursued informational support opportunities during her pregnancy. She recognized signs of pregnancy, understood the dangers of substance-related behaviours while pregnant, and identified when she was in labour. Although she received support from formal and informal sources, the majority came from formal sources (e.g., doctors and prenatal classes). She found that having supportive caregivers present, having autonomy, and receiving individually tailored information facilitated informational support. The main barrier she experienced was receiving unhelpful information. Our other participant also had an active interest in acquiring pregnancy-related knowledge, recognized her nausea as a sign of pregnancy, acknowledging the dangers of ingesting substances while pregnant, and realizing when she was in labour. Her main source of informational support was also from formal support services. The facilitators this participant reported were the presence of supportive caregivers and having medical professionals relay individually tailored information. Some barriers she experienced were a lack of autonomy and receiving unhelpful information.

Discussion/Conclusions

In this study, we found that our participants had interest in acquiring pregnancy-related knowledge and received informational support from both formal and informal sources. Key facilitators and barriers to obtaining informational support included the method of information transference, the presence of supportive caregivers, and the woman's level of autonomy. This study contains two main limitations. First, this is an exploratory study using data from two individuals; their experiences may not be generalizable to all mothers with IDD. Second, because data were collected for another purpose, there may be important aspects of informational support that were not discussed by the participants. However, as this is exploratory research, these findings will be able to inform future research projects, ultimately improving policies and creating resources more tailored to be more accessible for women with IDD.

Improvement in Mindful Parenting Following Participation in Cognitive Behavioural Therapy for Children With Autism Spectrum Disorder

Authors: Andrea Maughan, Priscilla Burnham Riosa, Victoria Chan, Carly Albaum, Jonathan A. Weiss

York University, Toronto ON

Correspondence: amaughan@yorku.ca

Objectives

Parents of children with autism spectrum disorder (ASD) can experience greater stress compared to parents of typically developing children (Estes et al., 2009). The use of a mindful parenting approach, which refers to intentionally and non-judgmentally paying attention to one's child and compassionately reflecting on one's parenting ability, has been shown to reduce stress in parents of children with ASD, improving their ability to parent effectively (Cachia, Anderson & Moore, 2016). There is evidence that parent involvement in child-focused therapy may indirectly improve parent's own functioning (Reaven et al., 2015), though parent outcomes are rarely measured in this context. The aim of the current study was to examine parent changes in mindful parenting, and associations with child outcomes, following participation in CBT for children with ASD.

Methods

Participants included 40 children with ASD (92.5% male), 8–12 years of age (M = 9.65, SD = 1.27) with at least average IQ (M = 104.08, SD = 14.45), and their caregivers (75% mothers), involved in a randomized controlled trial targeting child emotion regulation, comparing treatment to a wait-list control group. Data was collected one week prior to intervention, and one week following intervention completion. Mindful parenting was assessed using the *Interpersonal Mindfulness in Therapy Scale* (Duncan, 2007), which has subscales of awareness/attention, non-judgment and non-reactivity. Child psychopathology and adaptive skills were measured via parent report on the *Behavior Assessment System for Children, Second Edition* (Reynolds & Kamphaus, 2004).

Results

Post-intervention, there were significant improvements in the non-judgment subscale ($t(36) = -2.48$, $p = .02$). Controlling for baseline scores, parents in the treatment group improved relative to the waitlist group on total mindful parenting, $F(1,36) = 4.18$, $p = .048$. Finally, parent improvement in non-judgment was associated with improvement in child emotional selfregulation ($r = .43$, $p = .01$). Data collection is ongoing, and 15 additional child-parent dyads are expected to have completed the trial by April 2016.

Discussion/Conclusions

Findings will be discussed in relation to optimally involving parents in therapy for children with ASD to promote positive parent and child outcomes.

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An Investigation of Sibling Relationships: A Comparison of the Stresses and Uplifts of Adolescents of Siblings With Fetal Alcohol Spectrum Disorder and Down Syndrome

Authors: Lucas Millar, Shelley Watson
Laurentian University, Sudbury ON
Correspondence: swatson@laurentian.ca

Objectives

Having a child with a disability has a significant impact on the family. Though a large focus of literature highlights the stressors of parents who have a child with a developmental disability, siblings experience similar stressors (Gold, 1993; McHale & Gamble, 1989; Ross & Cuskelly, 2006). Little exploration has looked at the stress and behavioural relationship shared between siblings who have been impacted by living with a brother or sister with developmental disabilities, more specifically fetal alcohol spectrum disorder (FASD) and Down syndrome (DS). Past literature has suggested a negative experiential impact on siblings with a brother/sister with DS (e.g., Cuskelly & Gunn, 1993; McHale & Gamble, 1989). Researchers see that children of siblings with DS tend to have positive perceptions of their brother/sister (Baumann et al., 2005; Graff et al., 2012; Kaminsky & Dewey, 2001). There is little to no literature discussing sibling relationships and experiences of living with a child diagnosed with FASD, but as suggested by Olsen et al.'s (2009) research with parents of individuals with FASD, children may experience negative effects of living with a sibling with FASD. Because DS and FASD have a variety of behavioural characteristics, sibling experiences may vary in regards to how care is provided and followed. Also, how siblings adapt to specific behaviours may have an influence on sibling relationships. This study compares adaptation to stress amongst adolescents who have a brother or sister with DS or FASD. The uplifts and hassles reported by adolescents who have a sibling with DS or FASD are also compared.

Methods

Participants are male and female adolescent siblings (12 to 18 years of age) of biological or adoptive background without a developmental disability or intellectual disability. Participants must have a brother or sister with either DS or FASD. Participants will fill out two questionnaires. The Sibling Daily Hassles and Uplifts Scale assesses the frequency and status of hassles (a disruption or interference; i.e., behavioural outbursts or inconvenient appointments) and uplifts (positive events; i.e., sharing a toy) experienced by a sibling (Giallo & Gavidia-Payne, 2006). The Sibling Inventory of Behaviour Scale assesses sibling relationships in regards to behaviour expressed towards a sibling with either FASD or DS (Hetherington et al., 1999; Schaefer & Edgerton, 1981).

Results

The results of this study are pending. Data collection is still in process and will be completed between the months of January and February, 2016. Based on research with parents of individuals with FASD, it is anticipated that adolescent siblings who have brothers or sisters with FASD will have more sibling related stressors in comparison to brothers or sisters who have a sibling with DS.

Discussion/Conclusions

The results of this study will provide a greater understanding of sibling relationships, specifically adolescents who have siblings with either DS or FASD. Implications of this study include increased awareness of sibling stresses to government agencies, disability related organizations, and practitioners, with the hope that increased supports will be provided to families raising children with either DS or FASD.

Group Interventions for Parents of Adults With Intellectual and Developmental Disabilities: Group Interest and Participation

Authors: Jaffni Pagavathsing,[1,2] Arielle Dryer,[1] Yona Lunsky,[1,2]

[1] Centre for Addiction and Mental Health, Toronto ON
[2] University of Toronto, Toronto ON

Correspondence: yona.lunsky@camh.ca

Objectives

Parents of adult with intellectual and developmental disabilities (IDD) often experience high levels of stress and poor psychological and physical health outcomes. Despite this, very few interventions exist to help these parents. To address this issue, we offered parents free intervention groups. Parents were randomly assigned to either a mindfulness group or to a support and information group. The aim of this poster is to describe what parents hoped to gain from these groups and determine whether initial group interest affected parent's subsequent group participation.

Methods

Flyers advertising the groups were circulated to parents of adults with IDD through Developmental Services Ontario, Toronto region (DSO). As part of registration, 54 parents completed a questionnaire that asked about what they hoped to gain from the groups as well as whether they had a preference for one group or another. Parent hopes were qualitatively coded by two raters. Parents were also coded in terms of group preference once assigned to groups, into three mutually exclusive categories: open-interest, direct-match, no-match. Parents in the open interest group did not have a specific interest or were interested in both groups. Parents in the direct-match group were placed in the group that they were interested in initially. Parents in the no-match group were placed in a group that did not match their initial interest.

Results

In terms of what parents were hoping for by participating in groups, interest in gaining help for themselves was expressed by 28 parents (51.9%). For example, one such parent hoped to learn “a new way of relaxing and controlling my feelings.” Nineteen parents (35.2%) were interested in getting help for their child. As stated by one parent, she hoped to learn more about “services available to improve daughter's quality of life.” Fourteen parents were interested in making social connections (25.9%) with other parents. One parent stated that she wanted to “connect with other parents and share ideas.”

Slightly more than half of parents had an open interest (53.7%) and the rest of the parents were split between a preference for the information group (27.8%) and the mindfulness group (18.5%). Of the 44 parents who were assigned to a group following survey completion, 13 parents were assigned to a group that matched their preference, and eight parents were assigned to one that did not match their preference. Regardless of whether or not parents were in groups that matched their preference, most parents attended the majority of sessions. There was one drop out in both the direct-match and non-match group. For those parents that completed satisfaction questionnaires and were in the non-match group, it did not appear that they were unsatisfied with the intervention they received.

Discussion/Conclusions

Results reveal that parents of adult with IDD are interested in gaining a wide variety of supports from parent groups, including helping themselves, their child and making social connections. Although some parents may have initial specific group interests, our results suggest that these interests do not necessarily impact participation and can be subject to change.

"He's Not Leaving": Families Raising Adopted Adult Children With FASD in Ontario

Authors: Jenna M. Pepper, Shelley L. Watson, Kelly D. Coons

Laurentian University, Sudbury ON

Correspondence: JPepper@cheo.on.ca

Objectives

The transition from emergent adulthood to adulthood can be a period of increased challenges for individuals with disabilities and their parents (Arnett, 200; Kim & Turnbull, 2004). Parents' goals for their children focus on independent living, relationships, and employment (Henninger & Taylor, 2014). Children's transition into adulthood can impact a family's core functions regarding economic support and nurturance, which is considered a crisis in adaptation literature, and can result in significant perceived parental stress (Patterson, 2002). The majority of families raising children with fetal alcohol spectrum disorder (FASD) appear to be nonbiological families (Rowbottom, Merali, & Pei, 2010), but limited research has been conducted on the experience of adoptive families raising adult children with FASD in Ontario (Watson, Coons, & Hayes, 2013). Parents can act as protective factors for the development of their children's secondary disabilities and those who are having difficulty adapting to their child's transition into adulthood may require additional services (Streissguth et al., 2004). Therefore, the purpose of the present study is to identify the experiences of parents of adult adoptees with FASD, and to examine their needs as they are adapting to their children's transition into adulthood.

Methods

Twenty adoptive parents with at least one adult child with FASD were recruited through FASD support groups across Ontario. Using a convergent parallel mixed-methods design, informed by the Family Adjustment and Adaptation Response model (Patterson & Garwick, 1994), parents completed the Questionnaire on Resources and Stress – Friedrich's version (QRS-F) and a semi-structured interview (Friedrich, Greenberg, & Crnic, 1983). To gain a better understanding of parents' experiences, the interviews were analyzed using Interpretative Phenomenological Analysis (Lyons & Coyle, 2010). The QRS-F was analyzed using descriptive statistics. The questionnaire data and interview themes were then compared to triangulate interview analysis findings. Factors impacting family adaptation (i.e., capabilities and resources) were examined.

Results

Three major themes emerged through the IPA analysis that described areas of need for adoptive families: transition into adult housing, managing finances, and individual characteristics. Parents reported experiencing stress due to a lack of adult housing for their children, difficulty accessing adult services, and a lack of work environments that can support individuals with FASD. The QRS-F results validated those findings, indicating that parents were on average experiencing moderate levels of perceived stress (M = 24.6, SD = 9.5). The children were struggling with financial independence as well as making independent and responsible decisions, all of which pose barriers to the transition to adulthood. Fifty percent of participants' children exhibited behaviours consistent with emergent adulthood (e.g., financial dependence), even though they were over the age of 25 (i.e., the end of emergent adulthood).

Discussion/Conclusions

Providing parents assistance with the aforementioned issues will help balance the demands and capabilities related to their children's transition into adulthood, thereby facilitating parental adaptation. The results of this study will be used to inform Ontarian FASD formal and informal services of the unmet needs of families so that more tailored programs can be created to support families of adult children with FASD.

Maintenance of Memory Strategy Use in Children With Autism Spectrum Disorder (ASD)

Authors: Alex Porthukaran, Hadas Dahary, Busisiwe L. Ncube, Melissa Ferland, Thomas Rhee, James M. Bebko

York University, Toronto ON

Correspondence: alexp12@yorku.ca

Objectives

In children with ASD, low levels of active strategy use, which can help in learning and memory situations, are frequently reported compared to typically developing peers. Prior research has shown that although children with ASD are able to to use memory strategies when taught, on follow up (e.g., two to three weeks later), they revert to low levels of strategy use observed before the training began. We sought to determine how increasing the depth of training would affect the maintenance of memory strategies. In this study the focus was on rehearsal strategies, or the repetition of key information to be learned.

Methods

Forty children (verbal mental age > 4 years) were given multiple training sessions. 20 of the children had a previous diagnosis of ASD and 10 of those had a verbal IQ of below 70 (i.e., met the criteria for intellectual disability). Among the 20 without ASD, 10 also had a verbal IQ below 70. Participants were asked to remember a series of cards with pictures in order (ball, chair, spoon, etc.) and place matching cards in the appropriate order to indicate recall. During the strategy training phase, an examiner modelled appropriate rehearsal strategy use and encouraged the child to do the same. Training sessions continued until the child used rehearsal strategies spontaneously without prompting from the examiner (up to a maximum of five times). A follow-up session two to three weeks later tested maintenance and generalization of strategy use.

Results

Participants with a verbal IQ of below 70 (with ASD and without) required more than double the amount of training sessions (27.5 vs. 12.5). Further, 80% of the ASD group used rehearsal strategies at the follow-up (compared to only 35% before training; $t(19) = 2.88$, $p < 0.01$). Among those who retained the use of memory strategies, serial recall of the pictures increased to 96%, but for those who abandoned the strategy, recall did not change (67% to 64%).

Discussion/Conclusions

Children with ASD can be taught to use rehearsal strategies spontaneously, but in order to maintain these gains in strategy use, and subsequently better recall, multiple training sessions are required for the child to achieve spontaneous strategy use. The demonstrated maintenance of training gains and generalization to new materials were of particular note. The procedures can be readily adapted to educational settings for improving the learning and retention of children with ASD.

A Focus on Developmental Strength Capacity: A 10-Year Literature Review of Well-Being and Autism Spectrum Disorder

Authors: Victoria Stables, Priscilla Burnham Riosa, Victoria Chan, Andrea Maughan, Carly Albaum, Jonathan A. Weiss
York University, Toronto ON
Correspondence: jonweiss@yorku.ca

Objectives

Autism spectrum disorder (ASD) literature is often conceptualized as focusing mainly on pathology and problem-oriented behaviours. Furthermore, interventions for this population have focused on correcting deficits. In order to promote positive strengths in children and adults with ASD and their ability to thrive in their environments, there needs to be a greater integration of strength-based approaches in different areas of ASD research to optimize developmental outcomes for children. In the last four decades of neurodevelopmental disabilities research, there has been a trend that indicates an increase in a strength focus and a decrease in a deficit focus (Shogren et al., 2006). To date, no one has examined whether a shift toward a strength capacity focus has occurred in the ASD research literature. Because ASD is a life long developmental disorder, changes can occur in clinical presentation over time. Therefore, this study is an investigation of whether or not a strength capacity focus has increased in the last decade across developmental age groups. The purpose of this content analysis is to establish whether there has been a trend of positive, strength-related research in the ASD literature in the past 10 years. Secondly, the study will also examine whether there is a relationship between positive, strength research and different developmental age groups. A positive trend may reflect increases in early diagnosis, intervention, and supports for family climate, which lead to better well-being outcomes for ASD children.

Methods

Research studies from five well-known ASD journals were coded by four coders to determine the proportion of studies focusing on developmental wellbeing from 2004 to 2014. The articles were searched by issue to ensure they were sampled evenly across each publication year. Between 25% to 33% of articles from each journal issue will be randomly selected. Articles were coded along several criteria including: a main focus on well-being; the perspective (strengths, deficits or mixed); and developmental age group.

Results

Currently, 80% (*n* = 924) of the articles have been coded. Coding will be completed by January, 2015. Current results illustrate that 157 articles focused on well-being and among these articles most had a deficit (45.2%) or mixed (42.7%) perspective and few articles demonstrated a strength perspective (12.1%). Once coding is completed, we will report trends in developmental age groups.

Discussion

The findings of this study will reveal trends with respect to the study of well-being and developmental age groups in ASD literature, and inform future areas for research and practice. Trends associated with the amount of strength-capacity research and developmental age groups may reflect increases in early diagnosis, early intervention and supports for family climate.

An Updated Review of the Impact of March Break and Summer Program Funding on Caregivers of Children With Autism

Authors: Marilyn Thompson,[1] Carly A. McMorris,[2] Busisiwe L. Ncube,[2] Olivia M. Jon,[2] Jessica H. Abrams,[2] James M. Bebko,[2] Ginny Kontosic,[1] Layne Verbeek[1] Margaret Spoelstra[1]

[1] Autism Ontario, Toronto ON
[2] York University, Toronto ON

Correspondence: marilyn@autismontario.com

Introduction

Those raising children with autism spectrum disorders (ASDs) face unique challenges, with the severity of symptomatology varying within a wide range of behavioural, communication and social skill levels. Consequently, research indicates that parents of children with ASDs report higher levels of stress than parents of those with other developmental disabilities or parents of typically developing children (Estes et al., 2009; Weiss et al., 2012). Support programming such as respite service are often cited as major factors that aid to reduce parental stress (Cowen, & Reed, 2002); however, the financial burdens placed on families seeking such services can be overwhelming. Autism Ontario is a service provider and family advocacy centre for individuals and families affected by ASD in Ontario, Canada. In addition to other services, Autism Ontario offers families the opportunity to apply for funding that can subsidize children to attend external programs during March and summer breaks.

Objectives

The goal of the present study was to examine the impact of funding for ASD support programming and its perceived effect on parental stress levels. Additionally, this study will explore how funding was utilized by families, what programs children participated in, what skills were obtained by children with ASD, and most importantly, how these factors relate to parent's levels of stress.

Methods

An online survey was circulated to parents who had applied for March or Summer Break program funding from 2007–2011. A total of 695 caregivers of children with ASD completed the survey, 477 of whom indicated they had received either March or Summer break funding at least once during the 2007–2011 period. The survey obtained feedback related to basic demographic information, languages spoken by the families, years of Canadian residence, whether parents felt a reduction in stress, and how funding impacted their decision to enroll children in camps or seek respite help. Parents were also asked to describe the type of program in which their child participated (e.g., mainstream day or residential camps, autism-specific camps) as well as the length of time spent in each program. Respondents were asked if their child had made observable improvements in areas such as self-regulation, aggression, stereotypical behaviour, improved communication, and social interaction.

Results

Support workers accounted for over 25% of funding expenditure with 50% of families placing their child in programs lasting 5–7 days. Importantly, 31% of respondents stated they would not have been able to take advantage of support programs without subsidization. Approximately 78% of caregivers reported a significant decline in stress from their child's program participation. Finally, results revealed a wide-spread improvement for ASD children in social skills and increased interaction with others.

Discussion/Conclusions

The current findings highlight that the funding provided by agencies, such as Autism Ontario, offer a critical financial opportunity to those families who would not otherwise be able to afford these support services. Access to supplemental programming, such as residential and day camps, is reported to have significantly benefitted families and their children with ASD, shown by an improvement in skills and significant reduction in parent's stress.

Knowledge of the Effects of Gestational Alcohol Consumption and FASD in a Canadian Sample

Authors: Alexandra M. Zidenberg, Shelley Watson
Laurentian University, Sudbury ON
Correspondence: swatson@laurentian.ca

Objectives

When alcohol is consumed during pregnancy, it can lead to irreparable damage in the developing fetus (Walker et al., 2005). Excessive alcohol consumption by women during the gestational period is the leading cause of fetal alcohol spectrum disorders (FASD; Walker et al., 2005). Individuals with FASD experience common symptoms such as growth deficiencies, facial anomalies, skeletal deformities, speech and language deficits, motor dysfunctions, learning and behavioural difficulties, and sleeping and eating irregularities (Walker et al., 2005). FASD is one of the more common preventable developmental disabilities and one of the most common preventable causes of developmental disability (Townsend, Hammil, & White, 2015). In addition to the social and physical costs to the individuals, FASD also has a high cost to society. In the US, the median adjusted costs to society are approximately $3.6 billion (Lupton et al., 2004) and data for Canada is very similar with the National total ringing in at approximately $4 billion (Stade, Ungar, Stevens, Beyen, & Koren, 2007).

When asked, the majority of women know that alcohol is harmful to the developing fetus and should not be consumed during the gestational period (Peadon et al., 2010). Though people seem to realize that alcohol can be harmful during pregnancy, there is considerable confusion when it comes to what a “safe” amount is. Environics Research Limited (2000) found that for the most part, people were divided on their views of a “safe” amount of alcohol; for example, 47% of Canadians felt that drinking two alcoholic drinks on two or three occasions during pregnancy is safe, leaving 52% who disagree. As there is no amount of alcohol that has been proven to be safe, this is a very concerning finding (Beckett, 2011). Within the sample there were differences based on gender and province; men tended to be more likely to endorse higher levels of “safe” consumption during pregnancy, as were individuals from Quebec (Environics Research Limited, 2000). The purpose of this study is to gain knowledge of Canadians’ knowledge regarding alcohol consumption during pregnancy.

Methods

Participants will be Canadian men and women who are 18 years old and over. Participants will be asked to complete an online questionnaire regarding their knowledge of the effects of alcohol consumption during the gestational period (Environics Research Group Limited, 2000). Using this questionnaire will allow us to gain better insight into the knowledge of Canadians regarding alcohol consumption during pregnancy and to compare findings to the previous study.

Results

The results of this study are pending as the data collection will be undertaken during the months of February to April 2016. Based on the results of the Environics Research Group (2000) study, we expect to find that individuals will be confused about the specific harms and mechanisms of harm caused by alcohol.

Discussion/Conclusions

This study is important as it will contribute to the literature surrounding knowledge of the risks of drinking during the gestational period and FASD in Canada. In addition to the practical application of this research in the public health and medical fields, the current study aims to add much needed information to the literature regarding partner alcohol use and maternal alcohol usage patterns.

ABSTRACTS FROM THE 2016 RSIG RESEARCH DAY LONDON ON, APRIL 8 – PRESENTATIONS

Women With Intellectual and Developmental Disabilities: Their Perceptions of Others' Attitudes Toward Their Pregnancy

Authors: B. Mackenzie Barnett,[1] Lynne Potvin,[1] Hilary K. Brown,[2] Virginie Cobigo[1]

[1] University of Ottawa, Ottawa ON
[2] Women's College Research Institute, Toronto ON

Correspondence: mbarnett@cheo.on.ca

Objectives

Historically, childbearing among women with intellectual and developmental disabilities (IDD) was discouraged to the point of involuntary sterilization. There has been a shift in the last 40 years which recognizes all women's rights to retain their fertility and found a family. More women with IDD are now having children, however continue to face negative attitudes around childbearing. Women with IDD are a high-risk maternity population and require supportive prenatal care; their perceptions of others' attitudes may impact their likelihood to seek care, thus influencing their prenatal health. Our study aims to (1) describe how mothers with IDD perceive the attitudes of others toward their pregnancy, and (2) explore any perceived differences in attitudes of informal and formal support persons.

Methods

We used a descriptive case study approach. All transcripts of English-speaking participants (n = 2) from a larger qualitative study were analysed. Participants had IDD (as reported by developmental service agency staff), were older than 18 years at the time of the interview, had given birth in the last five years, and had sufficient verbal capabilities and memory recall to engage in an interview. Data were collected through semi-structured interviews. The interview included socio-demographic and pregnancy-related questions, a Social Circles Task to quantify formal and informal supports, and an adapted version of the Social Support Self-Report to describe perceptions of the quality of this support. We employed a content analysis framework to conduct an in-depth description of the two cases. Interviews and transcripts were reviewed in detail. Transcripts were then coded line by line in NVivo, using an open coding style. Matrices were used to extract relevant data.

Results

Preliminary results demonstrate two important findings. Firstly, both women perceived positive and negative attitudes from their informal and formal support persons. Reactions to the announcement of pregnancy were perceived as mostly positive and congratulatory from family and partners. Negative attitudes expressed by nurses were experienced in hospital before or after childbirth. Secondly, other personal characteristics of the women, separate from their disability, appeared to contribute to others' attitudes. One woman described her history with mental illness as the possible foundation of nurses' concerns. The other woman attributed her likeability and willingness to learn as explanation for why people in the community and service agency may have reacted so positively to her pregnancy.

Discussion/Conclusions

In this exploratory study, two women with IDD experienced largely positive attitudes from support persons. Personal characteristics other than their disability appeared to underlie others' attitudes. However, this was a case study, and both participants were part of the same developmental service agency; therefore, findings may not be representative of the experience of all women with IDD. Moreover, our data were originally collected for another purpose and therefore may not capture all the nuances of experienced attitudes. Nonetheless, this is one of the first studies to investigate the perceptions of women with IDD about others' attitudes. Our results suggest avenues for future research which could ultimately lead to improvements in service provider education and program delivery.

Understanding the Experiences of Parents and Children With ASD Who Attend the "Program to Assist Social Thinking" (PAST)

Authors: Priscilla Burnham Riosa, Jonathan A. Weiss
York University, Toronto ON
Correspondence: pburnhamriosa@brocku.ca

Objectives

Positive youth development (PYD) is a strengths-based perspective focused on fostering the following positive outcomes among youth: *Competence* (i.e., holding a positive view of one's actions within specific domains), *Confidence* (i.e., an internal sense of overall self-worth and self-efficacy), *Connection* (i.e., positive bonds with people and institutions), *Character* (i.e., respect for societal and cultural rules), *Compassion (Caring)* (i.e., showing sympathy and empathy), and *Contribution* (i.e., helping family, community members, and self) (Lerner, 2005). This resilience-based framework has been a model in interventions for typically developing youth, particularly in the United States (Catalano et al., 2004), although it has yet to be applied to programs for youth with autism spectrum disorder (ASD). The purpose of the current research is to understand the experiences of parents and children ages 8 to 12 years old with high functioning ASD who attend a novel school-based social-emotional intervention, the Program to Assist Social Thinking (PAST), from a PYD framework.

Methods

A total of 18 Year 3 PAST students and parents participated in our study. We conducted two focus groups with the children (n = 6 and n = 4). Focus groups involved: (1) a group discussion about PAST and (2) a drawing activity in which children were asked to draw their experiences of PAST. We conducted individual in-depth interviews with parents (n = 8) who described their experiences of the program. All interviews were audio-recorded and transcribed verbatim.

Results

Transcripts and drawings are being analyzed using thematic analysis (Braun & Clarke, 2006). Findings from our analysis will reveal themes highlighting the experiences of children with high functioning ASD who attend PAST and their parents.

Discussion/Conclusions

Our findings will underscore the importance of understanding the perspectives of children with high functioning ASD who attend PAST and their parents. The findings may have practice implications on the delivery of future iterations of the program and may inform the development of similar school-based social-emotional interventions for youth with ASD.

Fitness Trainer Perceptions of Disbility Changed Through Exercising With Adults With Autism Spectrum Disorder and an Intellectual Disability

Authors: Kelly Carr, Rebecca-Jane McAllister, Chad A. Sutherland, Sean Horton, Nadia R. Azar

University of Windsor, Windsor ON

Correspondence: carrk@uwindsor.ca

Objectives

Sociological theory suggests that prevailing assumptions of disability can be altered when exposed to individuals with disability acting in ways that challenge common perceptions. Given the lower levels of physical activity and fitness, and higher levels of obesity among individuals with autism spectrum disorder (ASD), participation in physical exercise by these individuals may exemplify one such behaviour that challenges dominant beliefs regarding abilities of people with ASD. In order to explore this avenue for social change, this study qualitatively examined the impact of volunteering as a personal fitness trainer for an adapted physical exercise (APEX) program designed for adults with ASD and an intellectual disability (ID).

Methods

Nine volunteers (undergraduate students from the Department of Kinesiology) of an APEX program completed one-on-one semi-structured interviews related to their experience as a personal fitness trainer for an adult with ASD-ID. Personal fitness trainers attended the APEX program two times per week, for a total of 12 weeks, with each session being 90 minutes in duration. Responsibilities included training APEX participants in a traditional exercise regimen which involved cardiovascular training on a stationary bike, strength training using weight machines and free weights, as well as coordinating sports and games participation. Verbatim transcripts of audio-recorded, semi-structured interviews were analyzed using inductive content analysis, and a constant comparison method was employed to organize common features between meaning units.

Results

The impact of volunteering as a personal fitness trainer for an APEX program was depicted through two broad categories: (1) challenging personal perceptions, and (2) shaping an inclusive future. Subcategories within "challenging personal perceptions" included *knowing the individual* and *emphasizing the capacity for growth*. Volunteers recognized that individuals with ASD-ID have unique personalities that are not defined by their diagnoses, a realization that challenged previous misconceptions. Additionally, through time spent with the APEX program, volunteers recognized the capacity of these individuals to learn new skills and complete activities that are typically set outside imaginable possibilities for people with disabilities. The second broad category entitled "shaping an inclusive future" included *building skills* and *creating a ripple effect*. Volunteers recognized that skills (e.g., patience, humbleness) learnt through supporting participants in the APEX program would benefit their future careers and volunteer positions pursued within the field of disability studies, aiding the development of an inclusive community. Moreover, APEX volunteers saw themselves as ambassadors of social change as they exposed other gym members to the abilities of individuals with ASD-ID. Through this exposure, volunteers noted reduced stigma toward individuals with ASD-ID within the gym setting, creating a ripple effect regarding the impact the APEX program has on shaping an inclusive community.

Discussion/Conclusions

Quality time spent engaging with individuals diagnosed with ASD-ID in an exercise setting had a positive effect on perceptions of disability by emphasizing the uniqueness and potential of the whole person with ASD-ID. It is through the development of personal qualities and skills suitable for interacting with individuals with disability, and positive exposure to people with ASD-ID that we can foster social change and create inclusive communities.

"The Larger Experience of Being a Sib Has Really Coloured and Influenced Who I Am": The Experiences of Individuals With Siblings

Authors: Marilia J. Carvalho, Shelley L. Watson
Laurentian University, Sudbury ON
Correspondence: mariliacarvalho229@gmail.com

Objectives

Sibling relationships foster social competence, overall adjustment and peer acceptance by providing a model for cooperation, and managing conflict. However, individuals who have siblings with autism spectrum disorder (ASD) are not frequently investigated within family research. When siblings are studied, maternal accounts about sibling interactions are often provided, which have shown discordance with sibling reports. Research also yields mixed findings. Potential risks of emotional and prosocial behaviour problems have been found in siblings of children with ASD, while other studies have found positive effects such as greater affection and lower levels of quarrelling. Thus, this study developed a balanced investigation of sibling interactions through first-hand accounts that can explain the nature of the relationship when one sibling has ASD.

Methods

Participants included 18 individuals who have a sibling with ASD. Participants ranged in age (6–54) and the majority were female. A mixed-methods approach consisted of two questionnaires and an in-depth interview. The Sibling Inventory of Behaviour Scale (SIBS) and The Sibling Daily Hassles and Uplifts Scale (SDHUS), both reliable and valid measures, assisted in quantifying problematic challenges or uplifts experienced by siblings. The qualitative component of the study, semi-structured interviews, were informed by a basic interpretive approach (Merriam, 2000) and captured the unique perspectives and personal accounts that can sometimes be lost in objective measures.

Results

Interpretative Phenomenology Analysis of interview transcripts yielded five themes across all interviews. Siblings in the sample "move through phases," experiencing prominent challenges such as problematic behaviour. However, only four participants described direct physical conduct, such as biting, slapping and/or kicking. "Coping Mechanisms" consisting of external networks and self-calming behaviours helped participants cope with difficult aspects, such as tantrums. While a majority of participants reported family and friends as support systems, very few participants accessed sibling support groups. "Shared Interests" was a recurrent theme, as it assisted participants in overcoming hassles and embracing more positive experiences with their sibling. A majority of siblings also voiced a new sense of "Growth" through feeling a greater sense of compassion and understanding of difference as a direct result of having a sibling with ASD. A commonality across all participants included a "Concern about the Future," where they discussed whether the same degree of care provided by parents could be given in later life. All siblings questioned the availability of resources and balancing their own responsibilities with caregiving roles. Quantitative data obtained through questionnaires was used to triangulate and further inform themes. An integration of qualitative and quantitative data is presented to provide a complete conceptualization of the sibling experience.

Discussion/Conclusions

Participants discussed both positive and negative sides to having a sibling with ASD, yielding a fuller understanding of what this experience is really like. Results consistently showed that siblings are concerned about the future caregiving for their brother or sister, especially due to a lack of available resources and familial discussion. With deinstitutionalization, many individuals with ASD are living with their families and most siblings are expecting to provide supports to their siblings once their parents can no longer provide care.

The study contributes to existing family literature by addressing paucities in our knowledge of siblings. Particularly, the results address the transition from a sibling role to that of caregiver, in order to inform tailored support programs for these individuals.

"It Seems Like a Pretty Reasonable Scenario, a Well Put Together Story": Using Vignettes as a Data Collection Tool With Health Care Students

Authors: Kelly D. Coons, Shelley L. Watson
Laurentian University, Sudbury ON
Correspondence: kharding@laurentian.ca

Objectives

Vignettes can be employed in research in a number of ways, including as hypothetical scenarios which are used to prompt responses to interview questions or to elicit an understanding of a participants' knowledge, attitudes, or opinions, based on their response to how they would behave in a hypothetical scenario. Vignettes have traditionally been employed as a data collection tool for quantitative research (e.g., Reiss, Levitan, & Szyszko, 1982; Reiss & Szyszko, 1983) or as a form of presenting the findings of qualitative, interview research (e.g., Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011). However, vignettes can also be uniquely used as a tool to *collect* research data, especially in conjunction with other data collection methods (e.g., qualitative, semi-structured interviews). As part of a larger, mixed methods study examining health care students' knowledge, attitudes, and self-efficacy regarding fetal alcohol spectrum disorder (FASD), health care students participated in one of three, scenario-based vignettes.

Methods

Modeled after vignettes created by Reiss and colleagues, and informed by previous findings from research with families raising children with FASD, three scenario-based vignettes were developed describing different scenarios regarding alcohol consumption during pregnancy. The vignettes include a number of differing characteristics, such as the age of the pregnant woman, the location in Ontario (e.g., rural, urban, Northern, Southern), the current trimester of pregnancy, the type, amount, and frequency of alcohol consumed (e.g., "low" drinking exposure, binge drinking episode), and the amount of social support available to the pregnant woman. Health care students (n = 18) responded to one of the three vignettes, which were rotated between interviews.

Results

The experience of using scenario-based vignettes as a data collection tool for understanding health care students' knowledge and self-efficacy regarding FASD will be discussed. The vignettes allowed the researchers to collect information regarding how students would behave in potential "real life" situations, based on the manipulation of variables that would not necessarily be possible in other types of research studies, such as observational research. In addition to interviewing students about their *perceived* knowledge and self-efficacy regarding FASD, the use of vignettes allowed students to demonstrate their perceived level of knowledge through a clinical application exercise. The vignettes were instrumental in understanding health care students' existing beliefs and prejudices about FASD, as well as their perceived selfefficacy and ability in applying their knowledge to practical, clinical situations.

Discussion/Conclusions

The use of vignettes to collect qualitative data is a creative and unique approach to data collection. By including scenario-based vignettes, there is a potential for knowledge mobilization to occur immediately, as the vignettes may be used as a case-based teaching tool. The need for case-based learning and training has previously been suggested as a key component in reducing the knowledge and application gap in clinical practice for FASD.

The F-Words in Childhood Disability: Embracing Opportunities for Knowledge Translation

Authors: Andrea Cross,[1,2] Peter Rosenbaum,[1,2] Danijela Grahovac,[1] Diane Kay,[1] Sue Baptiste,[1,2] Jan Willem Gorter[1,2]

[1] CanChild Centre for Childhood Disability Research, McMaster University, Hamilton ON
[2] School of Rehabilitation Science, McMaster University, Hamilton ON

Correspondence: crossac@mcmaster.ca

Objectives

In 2012, two *CanChild* researchers published: *"The 'F-words' in childhood disability: I swear this is how we should think!"* Building on the WHO's International Classification of Functioning, Disability and Health (ICF) framework, the article featured key strengths-based ICF themes – Function, Family, Fitness, Fun, Friends, and Future. This poster reports how the Diffusion of Innovation (DOI) theory has been used in the knowledge translation (KT) journey we have been on over the last four years to move the F-words ideas into practice.

Methods

DOI theory aims to explain *how* and *why* an innovation (or an idea) is adopted. It identifies four key factors that influence the adoption process: time, social networks, communication channels and the innovation itself. Our integrated team has used various communication channels (websites, social media, webinars, publications, presentations) to spread awareness of the F-words to multiple social networks, including international audiences. We have embraced opportunities presented to us for KT and learned about the importance of partnerships. All of our KT activities are performed in partnership with the knowledge users (i.e., parents and clinicians). Researchers, clinicians and families have found common ground in the F-words, and we believe by working together we can move these ideas into practice.

Results

To date, the article has had 6,395 downloads; there have been over 60 local, national, and international presentations; and the video has received over 2,000 views. There have also been multiple Facebook posts, tweets, online news articles (n = 8) and online blogs (n = 6), written by health researchers, physiotherapists, occupational therapists, and parents. Recently, we held a webinar on the F-words through the Canadian Association of Paediatric Health Centres (CAPHC), which attracted an international audience of mainly healthcare professionals. Subsequently, health care organizations in Ontario have been contacting us to run interprofessional workshops on the F-words and collaborative practice. This is an example of the power of communication channels and social networks, and the importance of recognizing and seizing opportunities as they arise.

Discussion/Conclusions

Knowledge translation is a process that takes time and commitment. We have come a long way from when the paper was initially published in July 2012, but still have a ways to go before the F-words are fully integrated into practice. We hope to continue to foster partnerships and to build opportunities for knowledge brokering. In order to reach a wider audience, our next step is to develop and evaluate the impact of an online F-words Knowledge Hub for families and service providers.

References and Resources

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CanChild "F-words" Knowledge Hub: www.canchild.ca/f-words

Digital Technology Use in Art Therapy With Adults With Developmental Disabilities

Authors: Olena Darewych,[1] Natalie Carlton,[2] Kevin Farrugie[3]

[1] Wilfrid Laurier University, Waterloo ON
[2] School of the Art Institute of Chicago, Chicago IL
[3] Private Practice

Correspondence: odarewych@wlu.ca

Objectives

Researchers have commenced examining the use of digital technology as communication devices with children and youth with developmental disabilities. Results from these studies have been mostly positive. This phenomenological art-based study on the other hand, explored the use of digital technology as an art medium and clinical intervention tool for adults with autism spectrum disorders and other developmental disabilities. The study explored the following two research questions: (1) How do adults with developmental disabilities experience digital technology as an art medium and a clinical intervention tool in art therapy? and (2) Which image making and creative activity applications are most suited for adults with developmental disabilities? It is critical to explore and evaluate how digital technology can be used as a viable creative and cost-effective device with this population in clinical settings.

Methods

Five male and three female adults (*N* = 8) between the ages of 24 and 49 participated in the study. Participants were diagnosed with a variety of disabilities, including autism spectrum disorders (*n* = 4), Down syndrome (*n* = 2), and a developmental disability not otherwise specified (*n* = 2). Participants attended five one-hour individual art therapy sessions during which they created on a Lenovo Yoga 13.3-inch Windows 8 Convertible Ultrabook™ and a Samsung 7-inch Galaxy Tab 3 Android touch tablet. At the end of each session, participants were asked the following question: "What did you like about the image making and creative activity application used today? Sessions were geared towards each individual's level of cognitive and physical ability and encompassed the following three segments: warm-up activity, art-based intervention, and closure activity. Artworks and session field-notes were the raw research data. Thematic analysis was utilized to determine common themes and patterns.

Results

Study results revealed the following six themes: a simple and mess-free digital canvas, independence, interplay of digital art and music, computer skills and cognitive development, voice and vision, and digital art directives. Participants with tactile sensitivity favoured creating art on the texture-free touchscreen devices. The three most favoured imagemaking applications among participants were Fresh Paint, Coloring Mandalas, and Sand Draw, while the two most preferred creative activity applications were PuzzleTouch and Sticker Tales.

Discussion/Conclusions

Adults with developmental disabilities are creative and imaginative individuals. Thus, it is important for clinicians to design and implement safe and innovative therapeutic settings for adults with developmental disabilities to express their thoughts and feelings verbally and non-verbally through the creative process. The benefits of digital technology in art therapy include portability, a multimedia communication platform to access photos and music from the Internet, and multiple image printing capacities. Future research with individuals of all ages with developmental disabilities is recommended in order to continue investigating the opportunities and challenges of digital devices as image making and creative activity tools in clinical settings.

My Life as an Epic Win: Self-Determination in Individuals With ASD

Authors: Allison Drake, Jeffrey Esteves, Kimberly Saldanha, Rebecca Ward
Brock University, St. Catharines ON
Correspondence: alliemdrake@gmail.com *or* Dr. R. Ward, Phoenix Centre for Learning, 437 Welland Ave., Suite 300, St. Catharines, ON L2M 5V2

Objectives

The transition into adulthood can be a difficult time for any young person. For individuals with autism spectrum disorder (ASD) who have challenges in communication, social interactions and executive functioning (DSM 5, 2013), this transition could be extremely difficult. Lower rates of post secondary school education and employment amongst young adults with ASD demonstrate the need for more programs to assist during this transitional period (Shattuck et al., 2012). The concept of "self-determination" has been central to research on understanding and improving outcomes for young adults with disabilities (Wehmeyer, Shogren, Zager, Smith & Simpson, 2010). Research has shown that higher rates of self-determination in teens with and without disabilities are associated with many positive outcomes in adulthood (Cobb et al., 2009; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015).For young adults with HFASD, there is little evidence for the effectiveness of teaching self determination on their adult outcomes (Wehmeyer et al., 2010; Shogren et al., 2015). To address this concern, in the winter of 2014, a 10-week course called *My Life as an Epic Win,* designed to teach self-determined behaviours (i.e., goal setting, action planning, actions attainment, and problem-solving) was delivered and evaluated for eight older teens and young adults with HFASD and their parents.

Methods

This study used a comparative case study design involving descriptive, interpretive analysis to describe the engagement of participants with protocols relating to self-determination. Specifically, qualitative within and across participant analyses of pre- and post-course measures of self-determination were used to explore the impact of the course on self-determination for three of the eight young adults with high functioning ASD who participated in the *My Life as an Epic Win* course. Two measures of self-determination were used (1) the Arc's Self-Determination Scale (SDS; Wehmeyer & Kelchner, 1995), and (2) Visioning and Action Questionnaire (VAQ), a self-report questionnaire exploring the participants' use of the self-determined behaviours taught in course.

Results

Analyses of these three case studies were useful in two ways. First, the analyses showed how these individuals with high functioning ASD already demonstrated self-determination prior to the course. Secondly, the analyses provided insight into how self-determined behaviours were enhanced through training for these participants. Separate from the case study analysis, procedural analysis provided guidance as to how the course could be improved to enhance future participants' acquisition of self-determined behaviours. As well, this procedural analysis identified ways to improve the research protocol to ensure the collection of complete and meaningful data for all participants.

Discussion/Conclusions

This study allowed us to evaluate the effectiveness of the course across three participants and helped us to develop further research questions that will be tested in future Epic Win research groups. Future directions of this research will be discussed. In conclusion, a course such as this can promote a "growth attitude," by encouraging participants to continue learning and experiencing situations that may be outside their comfort zone; leading them closer to their goals and ultimately, an *Epic Life*.

Self-Compassion and Psychological Outcomes in Parents of Adults With Intellectual and Other Developmental Disabilities

Authors: Arielle Dryer,[1] Jaffni Pagavathsing,[2] Richard P. Hastings,[3] Jonathan A. Weiss,[4] Yona Lunsky,[1,2]

[1] Centre for Addiction and Mental Health, Toronto ON
[2] University of Toronto, Toronto ON
[3] University of Warwick, Coventry UK
[4] York University, Toronto ON

Correspondence: yona.lunsky@camh.ca

Objectives

The purpose of this research is to explore the relationship between selfcompassion and psychological outcomes in parents of adults with intellectual and other developmental disabilities (IDD). Specifically, we sought to determine whether being selfcompassionate is related to negative psychological outcomes such as stress and depression, and positive psychological outcomes such as mindfulness and empowerment. We hypothesized that self-compassion would be negatively associated with stress and depression, and positively associated with mindfulness, mindful parenting and empowerment. In other words, we expected that parents of adults with IDD who are more self-compassionate would experience lower levels of psychological distress.

Methods

The sample consisted of 59 parents of adults or adolescents with IDD. Mean parent age was 56.51 (*SD* = 8.74), and mean child age was 22.94 (*SD* = 5.84). Of the 59 parents, 24 had a child with autism spectrum disorder, seven had a child with a genetic syndrome and six had a child with a comorbid psychiatric disorder. Parents filled out five separate questionnaires in either an online or paper format. Self-compassion was assessed using the Self Compassion Scale – Short form (SCS-SF; Neff, 2003), a 12-item self-reported measure. Depression and stress were assessed using the 7-item stress subscale and the 7-item depression subscale of the short-form Depression Anxiety Stress Scale (DASS-21; Henry & Crawford, 2005). The Bangor Mindful Parenting Scale (BMPS; Jones et al., 2014), a 15-item self-report measure, and the Five Facet Mindfulness Questionnaire (Baer, Smith, Hopkins, Krietemeyer & Toney, 2006), a 39-item self-report questionnaire, were adopted to assess mindful parenting, and mindfulness respectively.

Empowerment was assessed using the family subscale of the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992). The relationship between Self-compassion and psychological outcome variables was assessed using Pearson's correlation coefficients.

Results

Self-compassion was found to be negatively associated with stress ($r(57) = -.38$, $p = .003$), and depression ($r(57) = -.31$, $p = .021$). Additionally, self-compassion was found to be positively associated with mindful parenting ($r(55) = .59$, $p < .001$), mindfulness ($r(47) = .61$, $p < .001$) and family empowerment ($r(52) = .44$, $p = .001$).

Discussion/Conclusions

This study is the only one to date that has explored self-compassion in older parents of adults with IDD. Results supporting the relationship between self-compassion and psychological outcomes suggest that self-compassion is an important target of future intervention in this population. Older parents of adults with IDD face unique hardships as their children transition into adulthood, such as changes in service needs, limited service availability, and parents having their own health issues due to aging. An important target of future research would therefore be to examine whether interventions aimed at teaching and understanding selfcompassion can help parents in this population achieve better outcomes.

Teaching Categorizing Strategies to Children With Autism Spectrum Disorders to Assist Recall

Authors: Melissa Ferland, Gayle Goldstein, Alex Porthukaran, Hadas Dahary, James M. Bebko

York University, Toronto ON

Correspondence: melfer@yorku.ca

Objectives

The emergence and development of memory strategies are essential components of memory development and cognitive abilities (Schneider & Bjorklund, 1998; Schneider & Pressley, 1997). Memory strategies allow individuals to remember more information, by reducing the memory load. The majority of studies on memory strategies have focused on typically developing children and often on simple strategies such as rehearsal.

Very few studies have looked at the use of more complex memory strategies such as categorization and organization in individuals with autism spectrum disorder (ASD). Children with ASD are less likely to spontaneously use memory strategies, and they often do not use them effectively (Bebko & Ricciuti, 2000). Although strategies can be taught, children with ASD rarely maintain them over time (Cheung et al., 2010).

We explored effective methods of teaching categorization and organization strategies to children with ASD, and how to provide skills that are maintainable and generalizable across different cognitive tasks. We hypothesized that children with ASD could be trained to use these strategies, but our main focus was on what would be required for maintenance and generalization of them over time.

Methods

Nine children (age: 7–13) with ASD (Verbal Mental Age ≥ 4 years to ensure they could understand and complete the tasks) were divided into two groups in a multiple baseline design (group A and B). After baseline, all participants took part in two 45-minute training sessions per week for three consecutive weeks and a follow-up session three weeks later. During each of the training session participants were first assessed on a memory task in which they were presented with 12 cards from four categories (foods, animals) randomly arranged, and were told they could do anything they wanted with the cards to help remember them. The number of cards recalled and the strategy

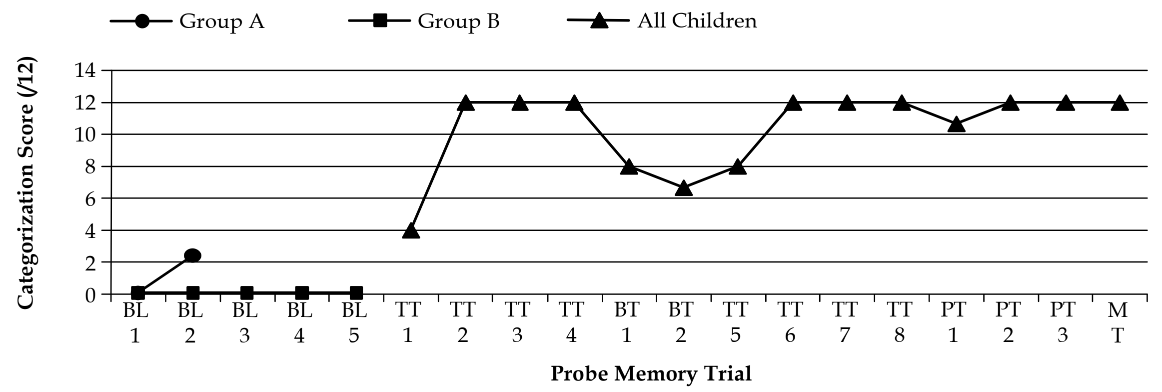

Figure 1. Average categorization scores

used by the child were recorded. The rest of the sessions involved strategy training where participants were carefully taught to use categorization and organizational memory strategies. Different games that benefitted from the use of memory strategies were used to test for generalization of skills.

Results

As seen in the Figure, during baseline (BL), no spontaneous categorization/organizational strategy use was observed. After one set of training trails (TT1-4), all the children used categorization successfully, but half did not maintain the skills in the between training sessions (BT trials). With only one more set of training trails (TT6-8), all the children used categorization successfully, maintained it on post-test follow-up trials (PT1-3) and when re-assessed three weeks later (MT).

Discussion/Conclusions

Organizational memory strategies can be readily taught to children with ASD using a carefully controlled procedure, leading to improved performance in learning situations. With these procedures, maintenance and generalization to new situations can occur. These methods can be easily adapted to educational settings for children with ASD. Being able to teach memory strategies to children with ASD in an efficient manner can help these children improve their recall and clustering capabilities which in turn can positively impact memory capacities and cognitive functioning.

When Did It Hurt the Most? Respite Providers' Perceptions of Painful Experiences in Children With Intellectual Disabilities

Authors: Tamlyn Freedman-Kalchman,[1] Lara Genik,[1] C. Meghan McMurtry,[1] Lynn Breau[2]

[1] University of Guelph, Guelph ON
[2] Glenrose Rehabilitation Hospital, Edmonton AB

Correspondence: tamlyn.freedman@mail.utoronto.ca

Objectives

Children with intellectual disabilities (ID) often struggle to provide accurate, consistent pain self-reports due to limited verbal communication abilities (Breau & Camfield, 2011; Dubois et al., 2010; Stallard et al., 2001). Thus, these children may rely on caregivers to assess and manage their pain (Breau et al., 2003). Little research has examined non-healthcare secondary caregivers' (e.g., respite workers [RW]) understanding of pain in children with ID. Our aim was to examine RW perceptions of pain intensity experienced by a child with ID in a number of painrelated situations. These perceptions could speak to RW ability to assess pain (understand pain communication and contextual factors) and is likely related to subsequent pain management decisions.

Methods

As part of a larger study on pain-related beliefs and care decisions for children with ID, 54 RW (45 female; Mean_{age}: 33.8 years; range: 18–67): (1) completed a series of demographic questions, (2) read four vignettes about a 10-year-old child with ID experiencing pain [pain related to headaches, arthritis, a fall, and an unknown source of pain; Genik et al., 2015], and (3) described when they believed the child experienced the highest level of pain intensity. Following the development of coding schemes and training, two research assistants coded participants' responses. Interrater reliability was calculated using Cohen's Kappa and frequency analyses were used to describe participants' responses.

Results

Cohen's Kappa ranged from 0.80–0.95, indicating substantial to almost perfect agreement. Across vignettes, participants believed that the most pain occurred during either (1) a single behavioural cue, e.g., screaming [range: 1.9%–50.0%], (2) a general event, e.g., when playing [range: 16.7%–79.6%], (3) a pain-related event, e.g., during headache [range: 0.0%–7.4%], or (4) when multiple indicators were present, e.g., squinches eyes and whimpers [range: 7.4%–16.7%]. Some participants did not believe or were unsure if the child had experienced pain (range: 1.9%–9.3%). When the pain was accidental, participants depended most on a general event to determine when the child experienced the most pain (e.g., "during the fall," 79.6% for fall vignette). However, when pain was chronic, participants depended most on specific aspects of the child's behaviour as a cue for when the child was experiencing the most pain (e.g., "when the child winced," 50% for arthritis vignette).

Discussion/Conclusions

Participants believed different cues and events could indicate when a child was experiencing the most pain. These ideas varied depending on the type of pain and scenario. For example, participants focused more on the general event leading to the pain for accidental pain, but more on the child's for chronic pain. The results demonstrate the need for RW to be flexible and vigilant with respect to the various cues they pay attention to when assessing pain. Investigation into how caregivers' perceptions of pain intensity in children with ID impacts pain assessment and subsequent management is warranted.

Improving Pain Assessment and Management Knowledge of Children's Respite Workers: Development and Preliminary Effectiveness of the "Let's Talk About Pain" Training Program

Authors: Lara M. Genik,[1] Meghan McMurtry,[1] Lynn Breau,[2] Stephen P. Lewis[1]

[1] University of Guelph, Guelph ON
[2] Glenrose Rehabilitation Hospital, Edmonton AB

Correspondence: lgenik@uoguelph.ca

Objectives

For children with intellectual disabilities (C/ID), pain is common, and understanding pain expression can be complex (Breau et al., 2003; Breau et al., 2007; Stallard et al., 2001). Efforts to improve pain assessment among caregivers of C/ID have focused largely on primary caregivers and health-care professionals. However, C/ID spend significant time with other secondary caregivers, such as respite workers (RW; Shelton & Witt, 2011). Standardized painrelated education for these caregivers has not been developed.

This presentation will discuss a two-phase study which first explored perceived pain training needs and format preferences of RW and managers using exploratory analyses. Second, a pain training program was developed and piloted. It was hypothesized that following completion of the training program, RW would demonstrate increased pain-related knowledge, improved perceptions of the feasibility of and confidence and skill in pain assessment and management, and also rate the program favourably.

Methods

For phase one, participants (n = 22; 19 female; M_{age}: 37.10; age range: 20–59 years) engaged in an interview or a focus group related to participants' experiences with pain in C/ID, perceived pain-related training needs, and program format preferences. Content and thematic analyses were used. Fifty RW participated in phase two (46 female; M_{age}: 33.20; age range: 20–59). Prior to the training, participants completed demographics, two knowledge measures (one adapted, one newly created) and provided self-reports of their perceived feasibility of and their confidence and skill in pain assessment and management for C/ID. Following the training, participants completed the same knowledge measures and ratings as well as a program evaluation questionnaire. Descriptive/frequency analyses and t-tests were used.

Results

In phase one, variable ideas about pain in C/ID were expressed, and participants rated their interest in and perceived value of a pain training program highly (range: 8.82–9.59 out of 10; 10 = Strongly Agree/Extremely Important). Informed by phase one, an in-person, half-day, interactive training program was developed. The program focused on what pain is, as well as pain expression, assessment and management in the context of C/ID and respite settings. In phase two, participants demonstrated significant increases in pain-related knowledge on both measures following completion of the pain training program (r = .81–.88). Participants' ratings of the feasibility of and their confidence and skill in pain assessment and management related to C/ID also increased (r = .41–.70). The training program was rated favourably overall (range: 8.61–9.15 out of 10).

Discussion/Conclusions

Participants' pain training needs and preferences were generally consistent with previous research literature (e.g., group-based training, Moreland & Myaskovsky, 2000; active learning, Prince, 2004). The created program showed promising results in terms of increased knowledge, confidence and skill. Strengths, limitations and future research directions (e.g., formal evaluation of the effectiveness of this training program through a randomized controlled trial) will be discussed.

Treatment of Problem Behaviours in Children and Youth With ASD and/or ID

Authors: Rebecca Goldreich, Adrienne Perry, Jonathan A. Weiss
York University, Toronto ON
Correspondence: rspiegel@yorku.ca

Objectives

Often, people with ASD and/or ID have "dual diagnoses," meaning co-occurring behavioural and/or mental health problems. Various treatment methods may be used which may or may not be evidence-based. In situations of behavioural crisis, youth may be taken to the Emergency Department as a last resort (e.g., Weiss, Slusarczyk, & Lunsky, 2011). The aim of the current research was twofold. First, we examined the presence and frequency of three problem behaviours (aggression, self-injurious behaviour (SIB), and mental health concerns) and whether/how they were treated. We expected that the more frequent the behaviour, the more likely it would be to receive treatment, more types of treatment, and more evidence-based treatment methods. Second, we examined the relationship between use of the Emergency Department and the different types of treatment methods used, for low and high frequency problem behaviours for each of the three behaviours.

Methods

Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) was a multi-year research project examining the health, wellbeing and social inclusion of children with severe DD. The current study uses information from 435 children and youth between the ages of 4 and 20 years (*M* = 11.43, *SD* = 3.87) whose parent completed the GO4KIDDS Basic Survey. We categorized frequency of problem behaviours into never, less frequent, and more frequent over the past 2 months. For each behaviour, parents were asked if the following treatments were provided: medication, formal behavioural program, informal behavioural/teaching strategies, OT/PT, diet/supplements, and expressive therapies.

Results

Preliminary analyses show that 56% of our sample display some degree of aggression, but only 45% of those are receiving one or more treatment(s) for it; 40% display SIB and 31% of those are receiving treatment; and 58% display mental health concerns and 41% of those are receiving treatment. Informal behavioural/teaching strategies was the most common type of "treatment" for all behaviours. In almost all cases, there is no relationship between the frequency of problem behaviour and either the type of treatment or the number of treatments. Other analyses are ongoing.

Discussion/Conclusions

A substantial number of children and youth display aggression, SIB, and or mental health problems. In each case, less than half of those are receiving treatment of any kind. Of those that are receiving "treatment," it is most often informal and not evidence based. There appears to be no relationship between the frequency of the behaviour and the number or type(s) of treatments used. In this poster we will discuss several possible explanations for these rather unexpected findings and their implications for clinical practice.

Sibling Relationships in Families of Children With Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, and Down Syndrome: A Comparison Study

Authors: Tara Hughes, Shelley L. Watson
Laurentian University, Sudbury ON
Correspondence: thughes@laurentian.ca

Objectives

Studies have shown that it is often a sibling who takes on the support and caregiving role in the life of a person with a developmental disability (DD) when the parent is no longer able to (Griffiths & Unger, 1994). However, very little research has examined how siblings adapt to their brother or sister with DD. To date there is also limited examination in regards to siblings of children with specific disabilities such as autism spectrum disorder (ASD) and Down syndrome (DS), and to the researcher's knowledge, no current studies investigating siblings of children with fetal alcohol spectrum disorder (FASD). Differences in the behavioural challenges posed by children with ASD, DS, and FASD are critical and to the extent that those difficulties vary across diagnoses, differences in sibling reactions are possible. It is important to make clear why siblings' experiences would be expected to differ as a function of their sibling's diagnosis, and if researchers can determine where siblings of children with specific disabilities struggle and where they are doing well, supports can be tailored to help lighten their experiences.

Methods

As part of a larger mixed methods research project examining the experiences of families raising children with ASD, FASD, and DS, this study will involve collecting, analyzing, and integrating both qualitative and quantitative data in one single study (Teddlie & Tashakkori, 2009). A total of 39 siblings participated; 15 siblings of children with FASD, 13 siblings of a brother or sister with ASD, and 11 siblings of individuals with DS. In-depth, semi-structured interviews were conducted, which were informed by a basic interpretive approach (BIA; Merriam, 2002). Participants also completed two quantitative questionnaires, the Sibling Daily Hassles and Uplifts Scale (SDHUS; Giallo & Gavidia-Payne, 2002, 2006) and the Sibling Inventory of Behaviour Scale (SIBS; Schaefer & Edgerton, 1981; Hetherington, Henderson & Reiss, 1999)

Results

Interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) was used to analyze interview transcripts. Five main themes were identified: positive transformational outcomes, sibling challenges, caregiving roles, awareness of disabilities, and formal supports. Questionnaire responses were also integrated to triangulate themes. Comparison findings between sibling groups from these questionnaires will be analyzed and discussed here.

Discussion/Conclusions

The results of this study provide a preliminary understanding of the lived experiences of siblings living with brothers and sisters who have been diagnosed with ASD, FASD, and DS. Results of this study will be helpful in developing and implementing appropriate supports for siblings of children with DD (e.g., sibling support groups, respite services) which may differ based on sibling diagnosis. Limitations and directions for research will be discussed.

Systematic Review of Mindfulness Interventions and Mindfulness Measures Used With the Autism Population

Authors: Sandra Salem-Guirgis, Carly Albaum, Jonathan A. Weiss
York University, Toronto ON
Correspondence: Sandra.salemguirgis@georgebrown.ca

Objectives

There is a growing body of research exploring the application and assessment of mindfulness in individuals with autism spectrum disorder (ASD). This poster presents an ongoing review of the literature on the evaluation of mindfulness within the ASD population. Specifically, we wish to understand how mindfulness is being qualified (i.e., how mindfulness is defined) and quantified (i.e., how mindfulness is being assessed), and examine how it is being used in interventions for individuals with ASD.

Methods

A review was conducted in accordance with the guidelines described by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009). A comprehensive list of search terms was developed by reviewing applicable literature and the thesaurus banks of each of the search drives for alternate but related terms used most frequently within each bank. The final list of search terms included mindfulness [mindful*, meditation, acceptance, (acceptance and commitment therapy), (dialectical behaviour therapy), buddhis*, Vipassana, Theravada, zen] and autism [autis*, (asperger syndrome), (pervasive developmental disorder), (developmental disabilit*), (autistic disorder)]. Articles were reviewed and included based on the following criteria: (1) the target population included individuals with a diagnosis of ASD, and (2) the intervention provided to the target population included a mindfulness component and/or mindfulness was assessed in the target population. Articles were excluded if they were: (1) not data-based (e.g., books, theoretical papers, or secondary reviews), (2) unpublished dissertations or theses, (3) not published in English, (4) examined populations that did not explicitly identify as having a diagnosis of ASD, or (5) reviews or meta-analyses of articles.

Results

An initial search of the databases using the search terms listed above yielded 1360 articles. A total of 12 articles out of the original 1,360 met inclusion criteria and are currently being examined for: (1) any measures reported to assess mindfulness, and (2) any interventions reported to include mindfulness-based therapy strategies. There were few studies that either used a mindfulness measure or mindfulness based intervention with the ASD population, and a preliminary review suggests few mindfulness measures are used.

Discussion/Conclusions

This poster will elaborate on these preliminary findings and discuss how mindfulness is currently being used and measured with the ASD population. Focus will be placed on the conceptualization of mindfulness and how it is related to the current use of mindfulness strategies and measures. Finally, an evaluation of the studies will be presented. Each of these topics will inform potential directions for future research in mindfulness with this population.

Treatment Adherence in ABA: Practices and Opinions of Behaviour Analysts

Authors: Meagan Scott, Rosemary Condillac
Centre for Applied Disability Studies, Brock University, St. Catharines ON
Correspondence: rcondillac@brocku.ca

Introduction and Objectives

Treatment adherence in Applied Behaviour Analysis (ABA), has been found to be positively related to treatment effectiveness (Fryling, Wallace, & Yassine, 2012). Yet studies such as Moore and Symons (2011) have reported that just under 25% of parents in their sample did not implement behavioural and/or medical intervention plans that they had been asked to follow for their child. Treatment integrity in general is not commonly reported in ABA research (McIntyre, Gresham, DiGennaro & Reed, 2007), Adherence to treatment recommendations by natural care providers in non-clinical settings is less frequently monitored and reported (Allen & Warzak, 2000). The purpose of this study was to begin address the dearth of research examining treatment adherence in practice by examining behaviour analysts self-report on their practices and opinions regarding treatment integrity and adherence.

Methods

Specifically an on-line survey was designed to collect information on behaviour analysts' practices when working families, staff, and educators of individuals with Intellectual and Developmental Disabilities, and to determine the extent to which the behaviour consultants were following best practices (treatment integrity), monitoring mediator treatment adherence. Further questions related to their opinions about the importance of treatment adherence and integrity in research and practice. This international survey was completed by 160 behaviour analysts with a wide range of educational backgrounds, years of experience, and differing certification levels.

Results

This study revealed some significant gaps between best practices and reported practices of behaviour analysts with respect to assessment methods, mediator training approaches on treatment plan, and objective monitoring of treatment adherence in practice. Despite these gaps, most analysts described their treatments as relatively effective in decreasing challenging behaviour and/or increasing replacement skills. Research has found that different treatment errors produce different impact on behavioural outcomes (St Peter Pipken, Vollmer & Sloman, 2010). The most common perceived barriers to treatment adherence in practice were focused on caregivers including burnout, lack of training and/or knowledge, and their prior learning history. This was interesting given that caregiver training and knowledge relating to intervention should be the responsibility of the behaviour analyst providing the intervention.

Discussion/Conclusions

This study reveals a training need for behaviour analysts and further research into the relationship between treatment adherence and outcomes in practice.

Sibling Experiences in Families of a Child With a Disability: Down Syndrome, Cystic Fibrosis, and Cerebral Palsy

Authors: Kristina Trandovski, Shelley L. Watson

Laurentian University, Sudbury ON

Correspondence: ktrandovski@laurentian.ca

Objectives

Raising a child with a disability can be stressful for parents and caregivers, but the experiences of the child's brother or sister is often overlooked (Stoneman, 2007). Siblings are emotionally influenced by each other during childhood, and this reciprocal influence continues into adulthood (Wennström, Isberg, Wirtberg, & Rydén, 2011). Down syndrome is a genetic condition that results in cognitive impairments and health conditions such as heart defects. Generally, siblings of individuals with Down syndrome describe their experiences as very positive, have lower levels of depressive symptoms compared to siblings of individuals with other disabilities, and perceive themselves as being better people because of their siblings with Down syndrome (Skotko, Levine, & Goldstein, 2011). Cystic fibrosis is a fatal genetic condition that causes a build-up of mucus in the lungs (Cystic Fibrosis Canada, 2014). Siblings of those with cystic fibrosis express positive feelings about their experiences, with the exception of feeling neglected due to their parents' focus on the child with cystic fibrosis (Havermans et al., 2010). Cerebral palsy is a permanent and non-changing disability that is seen in individuals with brain damage and results in motor impairment (Miller, 2005). Siblings of individuals with cerebral palsy often report having a number of responsibilities, such as being a secondary caregiver and teacher for their brother or sister, particularly into adulthood (Dew, Llewellyn & Balandin, 2014). This mixed methods study allows siblings to describe their experiences, including the hardships, rewards, and coping methods employed when having a sibling with Down syndrome, cystic fibrosis, and cerebral palsy.

Methods

Participants for this study will include 10 siblings to an individual with Down syndrome, 10 siblings to an individual with cystic fibrosis, and 10 siblings to an individual with cerebral palsy. Participants will be recruited through disability support and health organizations and word of mouth. Both biological and adoptive siblings are invited to participate. This study will employ a mixed methods approach (Johnson & Onwuegbuzie, 2004), consisting of a semi-structured interview and two questionnaires, the Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981) and the Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006). Responses on specific items and subscales will triangulate qualitative results to further understand the siblings' experiences. Interviews will be analyzed using Interpretive Phenomenological Analysis (Smith & Osborn, 2008).

Results

Data collection is currently ongoing. It is anticipated that siblings in the three groups will report similar stressors and uplifts as measured by the questionnaires, but there will be unique challenges as described in interviews. Preliminary analysis suggests that siblings of individuals with Down syndrome describe their experiences as positive and are willing to act as a future caregiver. It is expected that siblings of individuals with cystic fibrosis will see their brother or sister as if they did not have a disability, but may feel resentment because of the parents' focus on the child with cystic fibrosis. Finally, we anticipate that siblings of individuals with cerebral palsy will describe more demands compared to the other sibling groups and may reluctantly take on the role as caregiver.

Discussion/Conclusions

The results of this study will provide a better understanding of the experiences of individuals who have a sibling with a disability, and will fill the gaps within the literature, particularly adding to the limited research on siblings of individuals with cerebral palsy. Finally, this study will assist clinicians and disability service providers to develop appropriate services and supports for siblings of those with disabilities.