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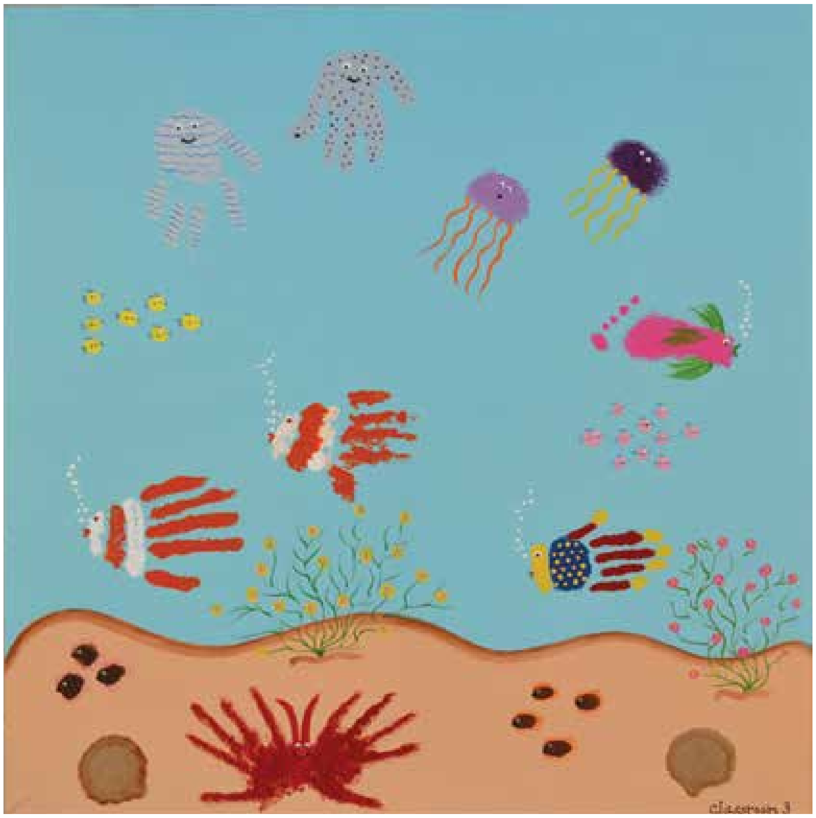

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Pilot Investigation of Language Development of Children With Autism Receiving Peer Networks Intervention

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expressive language,
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autism spectrum disorder,
peer networks,
language development

Abstract

Peer mediated interventions are among the most successful in producing positive change in social competence for individuals with autism spectrum disorder (ASD). The current study extends the research in this area by reporting the outcomes of a pilot study that sought to investigate the discrete changes in language skills of elementary school-age children with ASD enrolled in a peer mediated intervention. The peer networks intervention consisted of social groups and literacy groups with peers. Detailed language transcriptions of video probes were used to examine the impact of the peer networks intervention on expressive language abilities of eight children with ASD over kindergarten and first grade as compared to eight children with ASD not receiving intervention. Video probes were collected pre-intervention and at one and two years post intervention. Participants were separated into two groups based on baseline language capabilities: moderate and highly verbal. Change in participant's expressive language was measured by total number of completed words, total number of different words, mean turn length, and type-token ratios.[1] Findings indicate that the experimental groups made more gains in the observed language variables than the comparison groups for both the moderate and the highly verbal groups. Differences between experimental and comparison groups as well as between moderate and highly verbal groups were observed. Greatest differences were found in participants' total number of words and number of different words. These differences were strongest after two years of intervention. With intervention, participants communicated with their peers in a naturalistic social setting using a larger total number of words and a larger total number of different words than before receiving intervention and compared to participants not receiving intervention. Results from the pilot study further support the call for explicit instruction in social competence for individuals with ASD.

Autism spectrum disorder (ASD) is a lifelong pervasive developmental disorder that includes restricted interests and repetitive behaviours which can have significant impact on social interaction and social communication (American Psychiatric Association [APA], 2013). Social competence deficits are a core symptom of ASD (APA, 2013; Krasny, Williams, Provencal, & Ozonoff, 2003). Social competence deficits alone can greatly impact an individual's ability to form friendships and integrate meaningfully into society.

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[1] For definitions of mean turn length and type-token ratio, see Table 2

According to the National Professional Center on ASD (Wong et al., 2015) and the National Standards Project (Wilczynski et al., 2009), peer mediated interventions are among the most successful in producing positive change in social competence for individuals with ASD (Cappadocia & Weiss, 2011; Wang, Parrila, & Cui, 2012). These interventions are well suited for promoting a range of social skills development, such as increased initiations and responses to peers (Kamps et al., 2014a; Kamps et al., 2014b), improved affect (Carter, Hughes, Guth & Copeland, 2005), gaining attention (Thiemann & Goldstein, 2001), and increased appropriate talking (Chung et al., 2007).

Despite an impressive body of research on peer-mediated interventions, limited attention has focused on programming and generalization of skills within the context of peer inclusive groups such as those found in school settings. Further, few programs have addressed building social competence with peers combined with content area instruction (e.g., literacy) required for academic success (Mirenda, 2003). Recent work by Kamps and colleagues aimed to address this gap by combining a peer mediated social intervention with small group literacy instruction to create the peer networks intervention (see Kamps et al., 2014a; Kamps et al., 2014b). The current pilot study took place within the context of the development and implementation of the peer networks intervention, and the video probes that serve as the primary data source for this project were collected in the context of this project. The current study used these videos for transcription analysis so as to investigate language variance among study participants.

The focus of the current pilot study was to explore the impact of the peer networks intervention on participants' language development as well as what impact language skills might have on the peer networks study outcomes. Autism spectrum disorders present wide variability in language skills (Lord, Risi, & Pickles, 2004); many children with ASD have normal-to-advanced linguistic abilities while other children are markedly impaired (Tager-Flusberg & Joseph, 2003). Research suggests that most children with ASD have significant delays in acquiring language, with about half remaining functionally non-verbal (Bailey, Phillips, & Rutter, 1996; Tager-Flusberg & Joseph, 2003). Even children with ASD who do acquire the use of spontaneous language typically exhibit deficits in vocabulary and the acquisition of complex syntax (Bartak, Rutter, & Cox, 1975). Given the wide variability in language ability among individuals with ASD, we sought to evaluate this variable in more detail beyond the peer networks intervention study.

The Peer Networks Intervention

The pilot study reported here is part of the peer networks intervention (Kamps et al., 2014a; Kamps, et al., 2014b), a two-year intervention project that takes place from the beginning of kindergarten until the end of first grade. Using teacher-led, small groups (including neuro-typical peers) and peer-led play, the intervention includes a combination social and academic peer-inclusive interventions to improve social communication skills and early literacy as well as classroom survival skills (e.g., group participation, peer interactions) for young children with ASD. The intervention consists of two inter-related components: (1) Social Peer Networks focusing on social communication skills and (2) Reading Peer Networks focusing on literacy. The Social Peer Networks provides instruction and practice in critical social communication skills with peers and generalization programming to promote skill use across settings. The Reading Peer Networks provides a reading curriculum for small groups with peers using teacher-led direct instruction in early literacy skills and peer tutoring using supplemental reading activities. Supportive activities with peers provide multiple practice opportunities in literacy skills while providing social interaction with peers. The social peer networks and reading peer networks intervention components are described below.

Social peer networks. The peer networks intervention consisted of social groups to teach social and communication skills using games and age-appropriate play activities (e.g., card games, popular board games). Peer network groups were designed to provide structured interactions with typical peers using toys and games that allowed for multiple practice opportunities to improve reciprocal social communication (Kamps et al., 2002; Thiemann & Goldstein, 2004). Specific skills taught in the group included (a) requests and shares,

(b) comments about one's own play (activities, or personal actions on objects), (c) comments about others' play (activities, or peer actions on objects, (d) niceties (e.g., please, thank-you, compliments), and (e) play organizers (e.g., talk about ways to play, and taking turns).

Reading peer networks. The direct instruction curriculum *Reading Mastery* (Osborn, 1995) was selected for the Reading Peer Networks. *Reading Mastery* is intended for use in kindergarten through fifth grade. The curriculum helps develop decoding, word recognition, spelling, and comprehension skills through daily, explicit, systematic lessons that include teacher modeling, carefully selected examples, guided practice, repetition and elaboration (Osborn, 1995). *Reading Mastery* is designed for use with students with disabilities, including learning disabilities, mental retardation, behavioural disabilities, autism, developmental delay and traumatic brain injury.

Methods

The peer networks intervention, from which the current study is derived, has established success empirically in improving social communication skills for children with ASD (Kamps et al., 2014a; Kamps, et al., 2014b). This study sought to take a closer look at the discrete changes in participant's language development, taking into account their varying baseline language capabilities. The research questions (RQs) that guided the pilot study were: RQ1: How does participation in the peer networks intervention impact participant's language as measured by changes in participant's total number of completed words, total number of different words, mean turn length, and type-token ratios as compared to a control group? RQ2: How does participation in the peer networks intervention impact moderately verbal participant's language as compared to highly verbal participants? The Human Research Protection Program at the University of Kansas approved all methods and procedures included in the pilot study.

Participants

Sixteen participants were randomly selected from the larger peer networks intervention for participation in this pilot study. Due to the time-intensive nature of video transcription, a representative sample was selected from the larger sample. The inclusion criteria for the peer networks intervention included: (1) a confirmed educational identification of ASD through reports from school personnel or parent reports of clinical evaluations confirming autism; (2) moderate to high functioning level based on school reports of functional communication such as the ability to make requests, and use of two to three word phrases; (3) ability to follow simple directions; and (4) a standard score of 50 or greater on the Peabody Picture Vocabulary Test 4 (PPVT-4; Dunn & Dunn, 2007).

Study participants were classified into two groups based on the number of communicative acts (verbal initiation or response to a peer) evoked during three 10-minute baseline video probes. Students with 15–24 communicative acts were assigned to the moderate language group and those with 25 or more were assigned to the advanced language group. Baseline video probes were taken before the beginning of intervention. To ensure group similarity, experimental and control groups were matched on results from the Childhood Autism Rating Scale (CARS; Schopler, Reichler & Renner, 1988) and the PPVT-4. Table 1 provides detailed individual participant characteristics. In the text, individual children have been denoted by pseudonyms.

Pilot Study Design and Procedures

Pre-post measures were used to determine changes in expressive language skills between the participants enrolled in the peer networks intervention versus those in the comparison group. For a comprehensive overview of the methods and procedures of the larger peer networks intervention, see Kamps and colleagues (2014b). For the pilot study, video probes were collected at three different time periods: (1) during baseline, before the peer networks intervention began; (2) at the end of one year of intervention; and (3) after two years of intervention.

The video probes were designed to capture child-peer interaction and language use in more naturalistic social settings with multiple choices of games and activities. Each probe consisted of three students (one child with ASD and two neurotypical peers) at a table with pre-selected

Table 1. Participant Characteristics

Group	*Gender*	*Age*	*CARS Total Score*	*PPVT-4 Standard Score*
Experimental Highly Verbal				
Maria	F	5y 9m	23	104
Josh	M	5y 4m	39.5	89
Ellen	F	5y 11m	36	72
Jack	M	5y 6m	34	135
Comparison Highly Verbal				
Peter	M	7y 1m	34	84
John	M	5y 11m	24	112
Tricia	F	6y 0m	33	75
Joan	F	5y 11m	30.5	87
Experimental Moderate				
Rob	M	5y 10m	35	74
Evan	M	5y 11m	35	86
Andrew	M	5y 10m	27.5	77
Ryan	M	5y 6m	34.5	72
Comparison Moderate				
Joe	M	7y 6m	30	105
Anne	F	7y 6m	29.5	78
Bill	M	5y 0m	30	99
Mark	M	4y 11m	29	68

social games. The three games available during kindergarten were: Ned's Head®, a memory game, and a puzzle or card game. During first grade, Zingo® was substituted for Ned's Head. Children were told they could have 10 minutes of free play, and the only rules were: (1) stay at the table, (2) play with items on the table, and (3) be nice to your friends. The same set of social games was used for all nine video probes. There was no adult prompting or interruption for the 10-min probe. Participant interactions were video recorded by project staff for later coding and analysis.

A total of eight children with ASD comprised the experimental group, for which a total of 24 pre-intervention video probes, 24 mid-project probes, and 16 post-intervention video probes were collected. Similarly, eight children with ASD comprised the participants in the control group, for which a total of 24 probes were collected at the beginning of kindergarten, 24 at the end of kindergarten, and 16 at the end of first grade. Baseline video probes allowed for comparison of participants' expressive language abilities before and after the intervention. Treatment probes at the end of year one and at the end of year two allowed for comparison both between and within intervention phases of the groups.

The first author and two trained staff members transcribed the 128 ten-minute video probes. We adopted a language sample analysis approach (LSA), as this method of analysis is well established in the both the research literature and in clinical practice (Donaldson, 1986; Hart & Risley, 1995; Slobin, 1985; Southwood & Russell, 2004). LSA is used for describing language production and for monitoring change associated with linguistic development, variation in linguistic contexts, and change from intervention (Miller, Andriacchi & Nockerts, 2016). The Systematic Analysis of Language Transcripts (SALT; Miller & Iglesias, 2012) software package was used to facilitate the transcription of the video probes. Transcribers trained until they were able to achieve an 80% rate of agreement in their transcriptions. The transcripts were analyzed by using SALT's built-in "Standard Measures" analysis features. The standard measures that were used were Total Completed Words, Number of Different Words, Number of Total Words, and Type-Token Ratio. Table 2 provides operational definitions of these variables.

Inter-Observer Agreement

Inter-observer agreement was calculated for 32 (25%) of the transcription files. Best practice in single case research design recommends assessing inter-observer agreement for a minimum of 20% of all sessions (Kratochwill et al., 2010). Transcription files were randomly selected with equal representation from the moderate group (16) and the highly verbal group (16). Final agreement was 85.7%. Inter-observer agreement summaries are provided in Table 3.

Results

In this section, we present the data gleaned using the methods described above. Data in each sub-section are organized by experimental and comparison groups. Moderate participants' results are presented first, followed by highly verbal participants' results.

Total Number of Completed Words

For the moderate participants, total completed words (TCW) are represented in Figures 1 and 2. Figure 1 shows an increasing trend from baseline to year one probes and then a substantial increase from year one probes to year two probes for all four participants in the moderate experimental group. The moderate comparison

Table 2. Definitions of Systematic Analysis of Language *Transcripts [SALT] Language Measures*

Dependent Variable	*Definition*
Total Number of Completed Words (TCW)	The total number of words spoken.
Total Number of Different Words (TDW)	The number of different word roots.
Mean Turn Length (MTL)	The length of the conversational turn in a reciprocal conversation measured in number of words.
Type-Token Ratio (TTR)	A ratio of different words to total words (measures vocabulary variation). The "token" is the total number of words used and the "type" is the number of different words used.

Table 3. Inter-Observer Agreement for Highly Verbal and Moderate Groups.

	Experimental	*Control*	*Experimental & Control*
Highly verbal group	83.1%	85.5%	84.7%
Moderate group	82.5%	93.8%	86.6%
		Total Agreement:	85.7%

group (Figure 2) did not show the same increasing trend from baseline to year two probes. All four of the comparison group showed an increase from year one probes to year two probes for TCW, albeit not as pronounced.

For highly verbal participants, data for TCW are represented in Figures 3 and 4. Figure 3 indicates the highly verbal experimental group showed a similar pattern to the moderate group for TCW, with three participants showing an

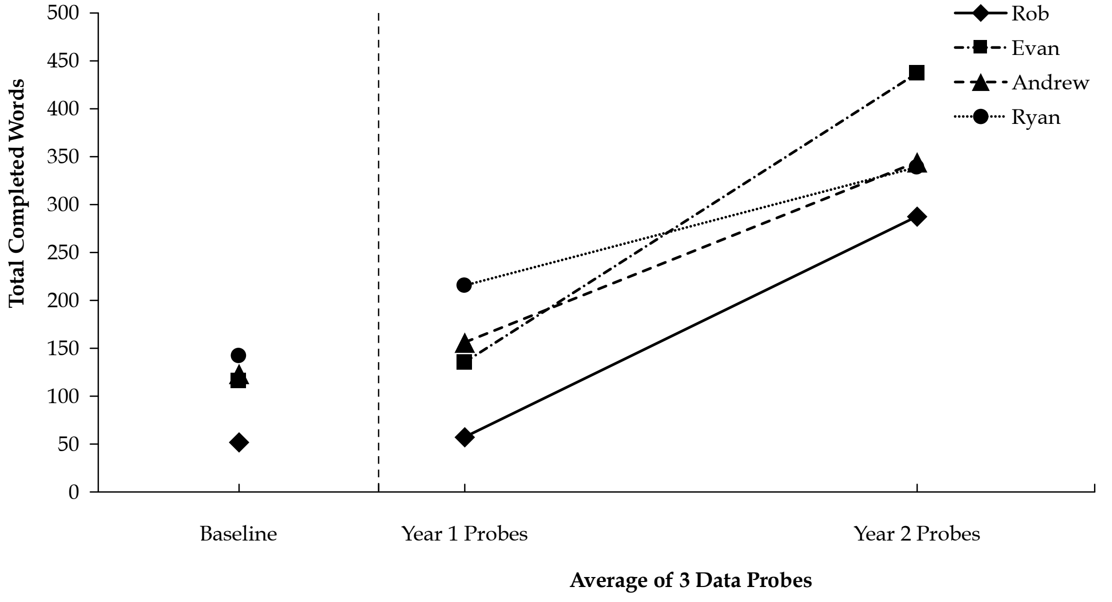

Figure 1. Total completed words – moderate experimental group

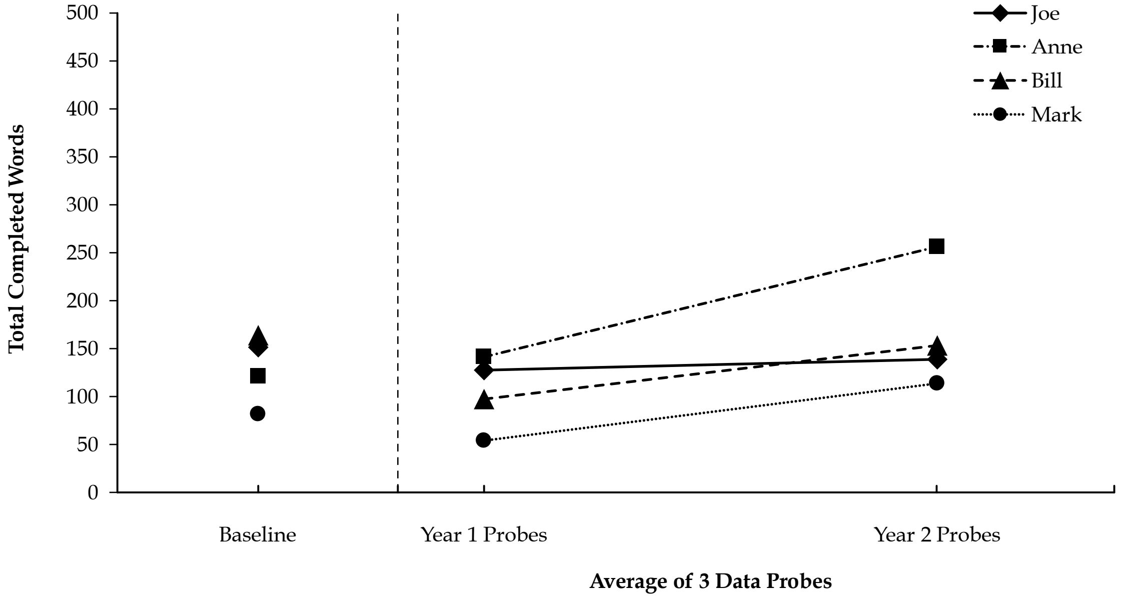

Figure 2. Total completed words – moderate comparison group

increasing trend from baseline through year two probes. The highly verbal comparison group exhibited variable results for TCW (see Figure 4).

Total Number of Different Words

For the moderate groups, data for total number of different words (TDW) is represented in Figures 5 and 6. With the exception of one

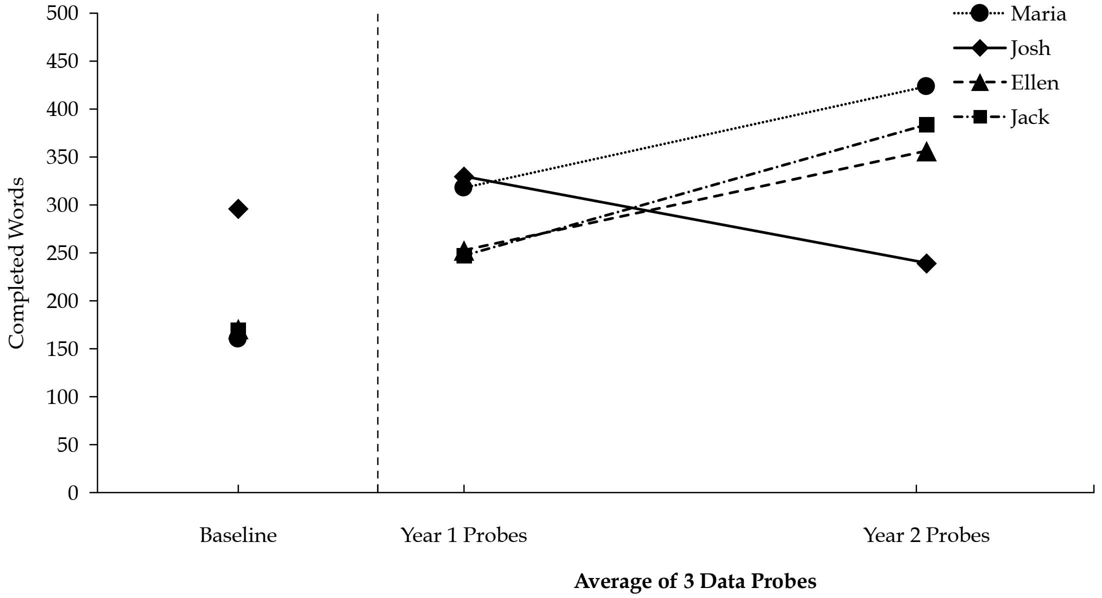

Figure 3. Total completed words – highly verbal experimental group

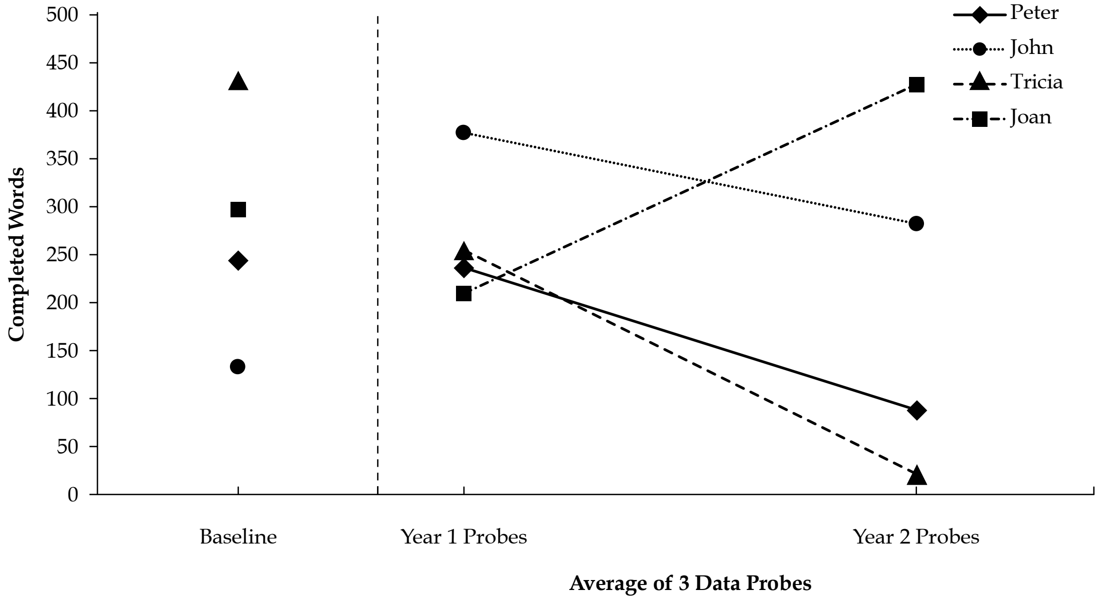

Figure 4. Total completed words – highly verbal comparison group

participant, all participants in the moderate experimental group showed the same increasing trend from baseline to year one probes and from year one to year two probes. In the moderate comparison group, only one student showed an increasing trend.

For the highly verbal groups, data for TDW is represented in Figures 7 and 8 on the following page. Figure 7 illustrates that Maria and Jack both showed an increasing trend from baseline all the way through the year two probes. Both Josh and Ellen showed an increase from baseline to year one probes but then decreased from year one to year two probes; however, their year two probes remained higher than baseline levels. The highly verbal comparison group again showed variable patterns among the participants (see Figure 8).

Type-Token Ratios

For the moderate participants, type-token ratios (TTR) are summarized in Table 4. In the moderate experimental group both Rob and Andrew increased TTR slightly in the year one probes compared to baseline levels but then decreased in the year two probes. Evan made no change from baseline levels to year one probes and Ryan decreased. Both Evan and Ryan's TTR decreased from year one probes to year two probes. A similar trend was found in the moderate comparison group. All participants in this group increased TTR in the year one probes from baseline levels, yet decreased from year one probes to year two probes.

For the highly verbal participants, TTR data are summarized in Table 5. In the highly verbal experimental group, Josh and Ellen increased their TTR in the year one probes from baseline and Maria and Jack decreased. All participants in this group had a decrease from year one to year two probes except for Josh. For the highly verbal comparison group Tricia and Joan made no change in the year one probes from baseline levels and John and Peter decreased. During the year two probes two students increased from the year one probes. John made no change and Joan had a decrease in her TTR.

Table 4. Moderate Group

Participants	*Total Number Completed Words*				*Total Number of Different Words*				*Type Token Ratio*				*Mean Turn Length*			
	B	*Yr 1*	*Yr 2*	*% +/-*	*B*	*Yr1*	*Yr 2*	*% +/-*	*B*	*Yr1*	*Yr2*	*% +/-*	*B*	*Yr1*	*Yr2*	*% +/-*
Experimental																
Rob	52	57	287	452	23	25	67	191	.62	.69	.30	-52	26	4	4	-85
Evan	116	135	438	277	44	42	120	172	.48	.48	.34	-29	4	3	7	75
Andrew	124	156	345	178	43	45	95	121	.55	.57	.43	-22	4	3	6	50
Ryan	142	216	339	138	68	95	142	109	.56	.50	.47	-16	9	7	10	11
Comparison																
Joe	115	128	139	21	58	71	61	5	.44	.59	.45	2	23	4	3	-87
Anne	121	141	256	111	58	63	107	84	.62	.63	.50	-19	3	4	4	33
Bill	164	97	153	-67	62	46	68	10	.53	.74	.56	6	4	3	4	0
Mark	82	54	114	39	39	28	40	3	.59	.66	.56	-5	3	3	4	33

Notes: Baseline (B) and Treatment 1 (Yr1) is the average of three data points and Year 2 (Yr2) is the average of two data points. % +/- is the percent change from baseline to year two.

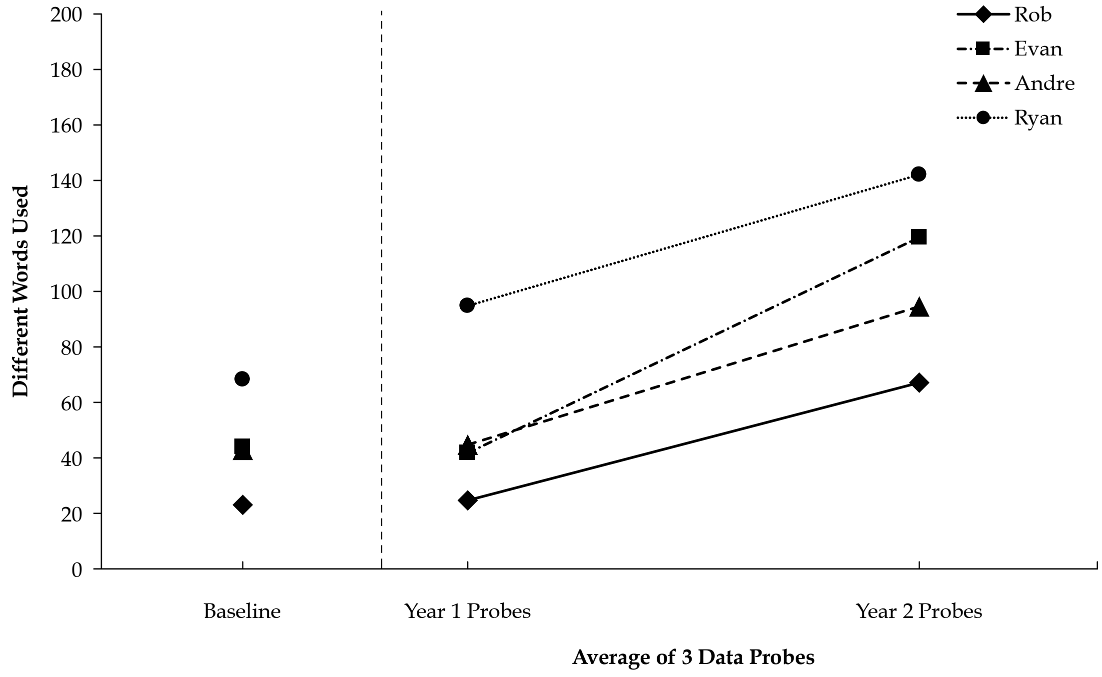

Figure 5. Total number of different words used – moderate experimental group

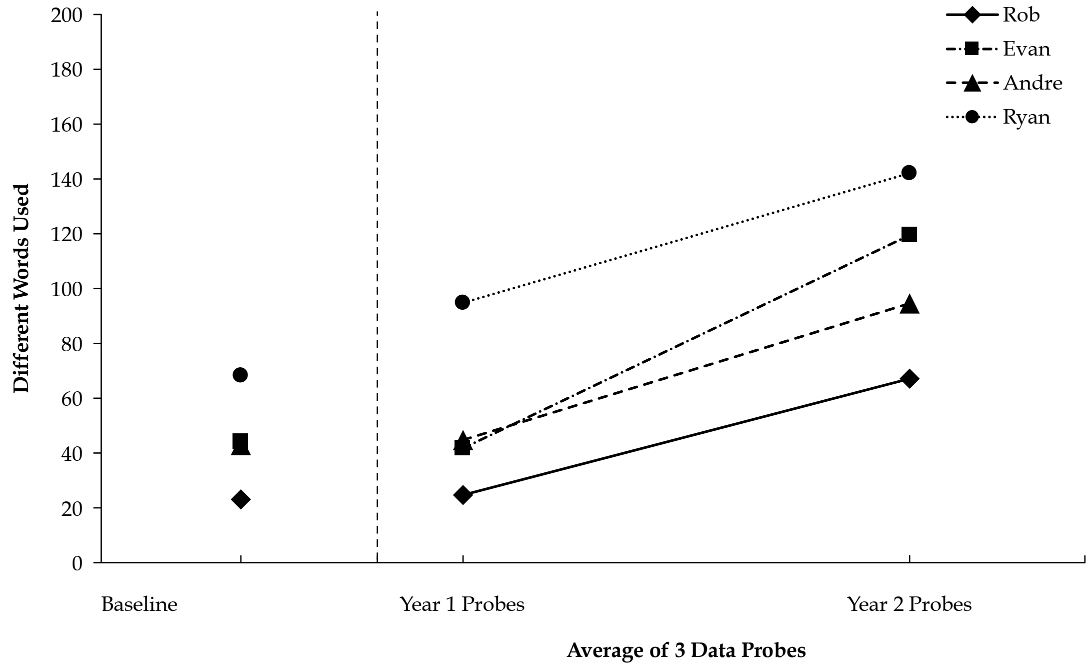

Figure 6. Total number of different words used – moderate comparison group

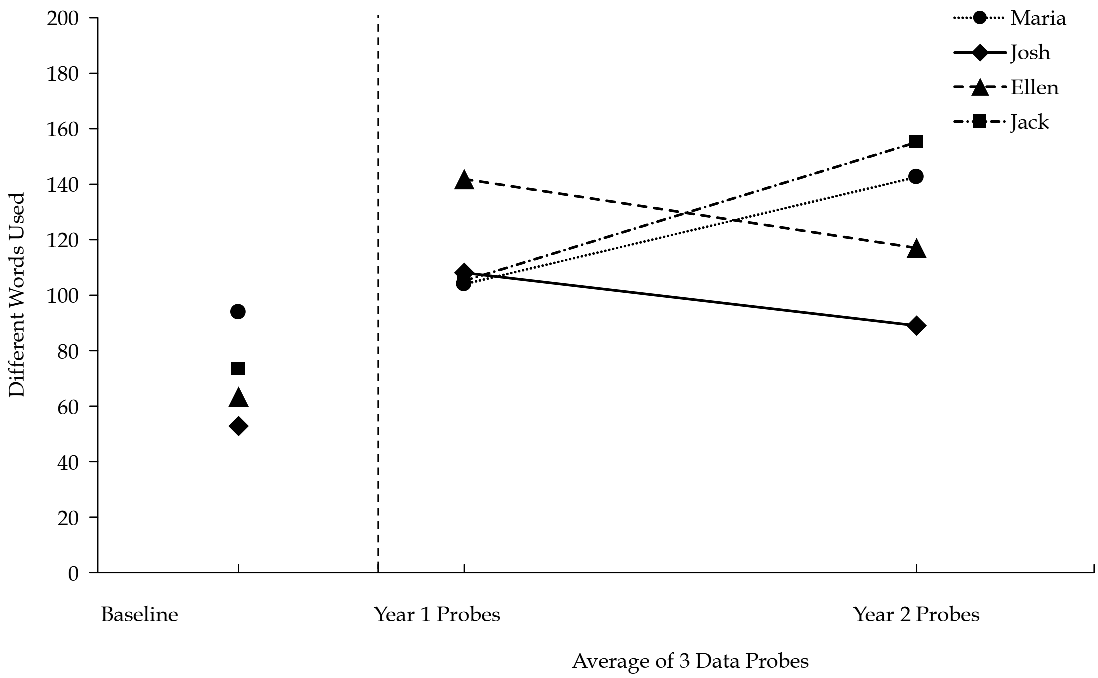

Figure 7. Total number of different words used – highly verbal experimental group

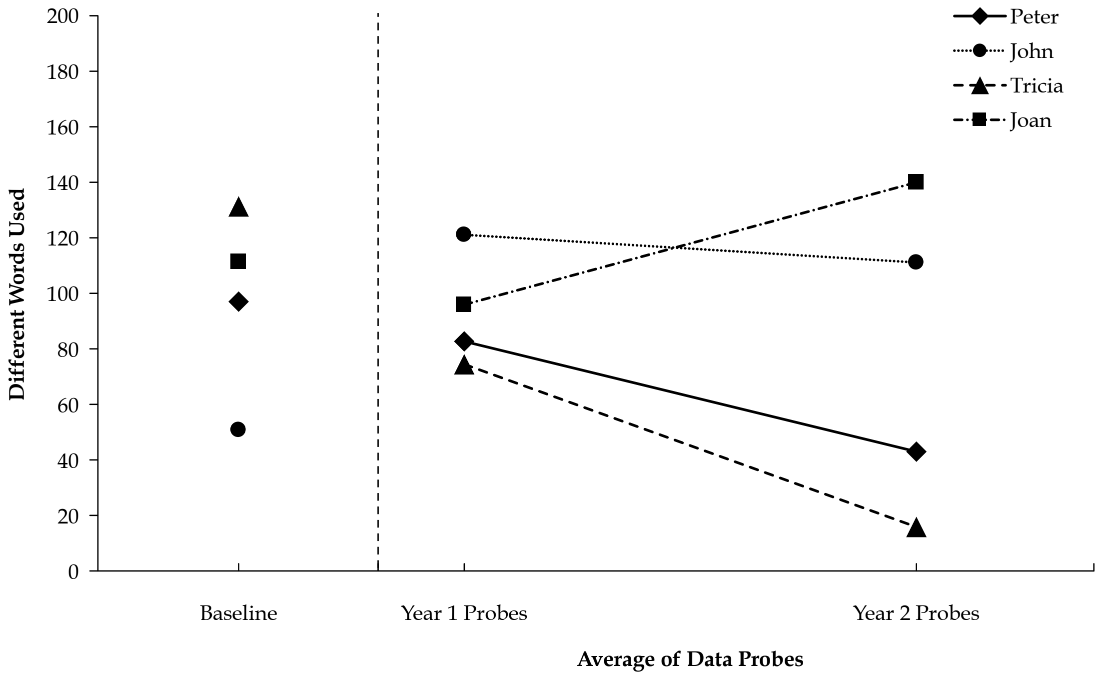

Figure 8. Total number of different words used – highly verbal comparison group

Mean Turn Length

For the moderate groups, mean turn length (MTL) is represented in Table 4. The trend indicates little change in the moderate experimental group from baseline to year two probes. Rob exhibited an extremely high MTL in baseline but then remained at much lower levels during year one and year two probes. The other three participants made very slight improvements when comparing year two probes to baseline. The moderate comparison group's data present a similar trend. Joe had an extremely high MTL in baseline but decreased to much lower levels in year one and year two probes. There was almost no change in MTL for Anne, Bill, or Mark.

For the highly verbal groups, MTL is represented in Table 5. Similarly to the moderate groups, both the highly verbal experimental and the comparison groups showed very little change in MTL from baseline to year one probes and from year one to year two probes. The most substantial change is seen in Tricia's data from year one to year two probes, increasing from an average of 5 words per conversational turn to 21 words per conversational turn.

Discussion

This pilot study sought to explore discrete changes in language development of peer networks intervention participants. The specific questions that guided this study focused on how participation in the peer networks intervention might impact participant's language as compared to a control group (RQ1) and moderately verbal participants' language as compared to highly verbal participants (RQ2). Four primary findings emerged from data analysis: (1) differences were found in observed language variables between experimental and comparison groups, (2) participants in the moderate experimental group made greater gains than those in the highly verbal experimental group, (3) gains observed for all experimental groups for the TCW and the TDW variables were greater, in general, from year one to year two than from baseline to year one, and (4) measures of TTR and MTL showed no noticeable changes across groups and conditions.

The experimental groups made more gains in the observed language variables than the

Table 5. Highly Verbal Group

Participants	*Total Number Completed Words*				*Total Number of Different Words*				*Type Token Ratio*				*Mean Turn Length*			
	B	Yr1	Yr2	% +/-	B	Yr1	Yr2	% +/-	B	Yr1	Yr2	% +/-	B	Yr1	Yr2	% +/-
Experimental																
Maria	161	318	424	163	94	104	143	52	.43	.38	.36	-16	13	6	8	-38
Evan	116	135	438	277	44	42	120	172	.48	.48	.34	-29	4	3	7	75
Andrew	124	156	345	178	43	45	95	121	.55	.57	.43	-22	4	3	6	50
Ryan	142	216	339	138	68	95	142	109	.56	.50	.47	-16	9	7	10	11
Comparison																
Joe	115	128	139	21	58	71	61	5	.44	.59	.45	2	23	4	3	-87
Anne	121	141	256	111	58	63	107	84	.62	.63	.50	-19	3	4	4	33
Bill	164	97	153	-67	62	46	68	10	.53	.74	.56	6	4	3	4	0
Mark	82	54	114	39	39	28	40	3	.59	.66	.56	-5	3	3	4	33

Notes: Baseline (B) and Treatment 1 (Yr1) is the average of three data points and Year 2 (Yr2) is the average of two data points. % +/- is the percent change from baseline to year two.

comparison groups for both the moderate and the highly verbal groups. The most significant changes were seen in the TCW and the TDW dependent variables. This indicates participants receiving the peer networks intervention communicated with their peers in a naturalistic social setting using a larger total number of words and larger total number of different words than before receiving intervention. These results suggest that the specific social communication skills taught in the peer networks intervention (requesting, commenting, play organizer etc.) could have resulted in changes for participants in the experimental groups. Additionally, these findings provide some evidence that skills acquired during intervention may have generalized to a non-instructional setting. This finding is promising in general, given that a noted concern in the literature is a lack of generalization of social skills learned during intervention (Bellini, Peters, Benner, & Hopf, 2007; McConnell, 2002; Rao, Beidel, & Murray, 2008), and for the peer networks intervention specifically, since the true efficacy of any social skills intervention is the generalization of skills to novel settings (Bellini, et al., 2007).

Findings also suggest that gains in TCW and TDW, both in the moderate and in the highly verbal experimental groups, were stronger after the second year of intervention. This underscores the importance of continuous, comprehensive social programs for children with autism in the early elementary years and beyond. We do not claim the peer networks intervention becomes more effective over time. Indeed, it could be the case that participants are simply developing naturally and their language abilities are developing concurrently. However, most individuals with ASD do not independently develop social competence (Krasny et al., 2003). Research indicates that a lack of these skills can lead to negative outcomes in adulthood (Gutstein & Whitney, 2002; Howlin, 2004), such as an inability to secure and maintain employment (Taylor & Seltzer, 2011), live independently (Szatmari, Bartolucci, & Bremner, 1989), and have intimate relationships (Howlin, Mawhood, & Rutter, 2000), as well as a number of other risk factors (Howlin, 2004). In order to ameliorate these potential problems, it is imperative that social competence programming becomes a central and ongoing focus in the educational planning for students on the autism spectrum. However, future research would benefit from a better understanding of the contexts and conditions under which the gains here were made.

The second research question looked at differences in observed language variables between participants in the moderate and the highly verbal groups. Our findings showed that the moderate group made more substantial gains overall than the highly verbal group. The difference in gains may be due to the language deficits of the moderate group being more appropriately matched to the design of the intervention. In the future, in order to increase intervention outcomes for participants considered "highly verbal," the peer networks intervention might consider screening language capabilities before intervention so that more individualized instruction could be created to meet specific needs. This consideration is in line with research on individualized instruction as a best practice for educating students with autism (Iovannone, Dunlap, Huber, & Kincaid, 2003; McConnell, 2002; National Research Council, 2001; Stichter, Randolf, Gage, & Schmidt, 2007).

A final finding was that very little change was observed in the TTR and MTL measures. As noted in Table 2, TTR is a ratio of the measure of vocabulary variation. The "token" is the total number of words used and the "type" is the number of different words used. The higher the variation in vocabulary, the higher was the ratio. MTL is the length of the conversational turn measured in number of words. There may be several reasons that gains were not evident in these two variables. First, language variability is not *specifically* targeted in the peer networks intervention. The goal is to increase social interaction with peers *in general*. Second, the scripted social group lessons used in the peer networks intervention used specific language scripts to prompt language use. Children with ASD can be very literal in their interpretation of social information and may not have deviated from the provided scripts. This could account for both the lack of variability (TTR) and the lack of growth in the MTR.

This pilot study was limited primarily by its design and small sample size. Because the study took place within a larger research project, data analysis occurred after the experiment was completed and assessment procedures were standardized to monitor social outcomes, without specific language variables. Data collection limitations were particularly problematic during the end of year two; only two video probes were collected. All other data collection periods consisted of three video probes, therefore impacting the comparison of data between these time periods. Future studies would benefit from using a more rigorous research design, with a larger number of participants. Finally, researchers could not control for maturation effects on language development over the two years of intervention.

In summary, this study reports the outcomes of a pilot study using a subset of participants enrolled in the peer networks project. The focus of the study was to explore the impact of the peer networks intervention on advanced and moderate language ability. Unlike other studies investigating social competence with individuals with ASD, we adopted a language sample analysis approach (SALT) that would afford a more discreet analysis of the change in participant's verbal behaviour. Results indicated differences between experimental and comparison groups as well as between moderate and highly verbal groups. The greatest differences were found in participant's total number of verbalized words and number of different words spoken. These findings suggest the utility of this method of analysis. Future research might consider this level of language assessment in social competence intervention planning and evaluation.

Key Messages From This Article

People with disabilities. Peer networks are an intervention strategy that has proven effective in improving social communication skills for children with autism spectrum disorder. You deserve to have meaningful social relationships. Peer networks may be able to provide the skills necessary to form and maintain these social relationships.

Professionals. Peer mediated interventions have proven effective in improving social communication skills for children with autism spectrum disorder.

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Teaching Staff Who Work With Children With Autism Spectrum Disorders to Evaluate the Treatment Integrity of Discrete-Trials Teaching Sessions

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Abstract

The current study evaluated the effectiveness of a self-instructional package to teach individuals to evaluate the treatment integrity (the degree to which intervention is implemented as planned) of discrete-trials teaching (DTT) sessions using the Discrete-Trials Teaching Evaluation Form (DTTEF). Participants were six staff from the St.Amant autism programs. We used a modified multiple-baseline design across a pair of participants, and replicated across two more pairs. At Baseline, a participant reviewed the 20-item DTTEF and a one-page summary of how to use it; they then attempted to assess the accuracy of DTT applied by a confederate role-playing an instructor teaching three tasks to a confederate role-playing a child with autism spectrum disorder (ASD). During training, participants studied a self-instructional package for using the DTTEF. At Post-training, participants were reassessed on the same tasks as during Baseline. During Generalization, participants were assessed evaluating the treatment integrity of three videos of an autism tutor administering DTT to a child with ASD. During a seven-month Follow-up, four participants were available and were reassessed. Training time averaged 1 hour and 16 minutes and mean accuracy increased from 47.6% in Baseline to 84.7% at Post-training. All participants showed excellent generalization results, and three of the four participants during Follow-up performed at a high level.

Treatment integrity is the degree to which an intervention is implemented as planned. If a behavioural intervention is administered with low treatment integrity, then the outcome cannot be interpreted with confidence (DiGennaro Reed & Codding, 2014). Although there have been numerous studies teaching individuals to administer discrete-trials teaching (DTT) (e.g., Arnal et al., 2007; Thiessen et al., 2009; Salem et al., 2009; Thomson et al., 2012; Wightman et al., 2012), few studies have examined methods to teach supervisors to evaluate the treatment integrity of such interventions applied by front-line staff (e.g., Peterson, Homer, & Wonderlich, 1982; Gresham, Gansle, & Noell, 1993; Wheeler, Baggett, Fox, & Blevins, 2006; McIntyre, Gresham, DiGennaro, & Reed, 2007).

Research has demonstrated that early intensive behavioural intervention (EIBI) is an effective treatment for some children with autism spectrum disorders (Matson & Smith, 2008; Matson & Sturmey, 2011). However, there is a paucity of published information on instructor treatment integrity in EIBI, and specifically, on DTT, a main EIBI procedure.

In DTT an instructor administers a series of approximately 10-20 teaching trials, with brief inter-trial intervals, before providing a brief break. DTT has been effective for teaching a variety of behaviours to children with ASD (e.g., Smith, 2001). Across the research evaluating DTT training, it has been noted that the number and type of DTT components that are assessed for treatment integrity vary, are not always stated, are very brief in description, and are not consistently applied (e.g., Carroll, Kodak, & Fisher, 2013; Thomson, Martin, Arnal, Fazzio, & Yu, 2009).

To address the need for a valid and reliable method to evaluate the treatment integrity of a DTT session with a child with autism, Fazzio and colleagues observed a large number of training sessions administered by staff of the St.Amant autism programs in Manitoba, Canada, a government funded program that Provides E|IBI services to children with ASD. They then developed a 19-item checklist called the Discrete-Trials Teaching Evaluation Form (Fazzio, Arnal, and Martin, 2007a) along with the DTTEF Scoring Manual (Fazzio, Arnal, & Martin, 2007b). The 11-page manual provides correct and incorrect descriptions on instructor behaviour and is used to train DTTEF users. However, no research has been conducted to evaluate this manual.

The DTTEF is divided into five parts and has been modified to include 20 DTT items (Fazzio, Arnal, & Martin, 2012; see Figure 1). It has been demonstrated to: (a) possess high face validity; (b) possess high interobserver agreement; (c) distinguish between untrained and trained individuals who were implementing DTT; (d) possess concurrent validity; and (e) be high in social validity (Babel, Martin, Arnal, Fazzio, & Thomson, 2008; Jeanson et al., 2010).

Currently, the DTTEF is the only researched tool, proven to be valid and reliable, for assessing the treatment integrity of DTT sessions. In order to teach readers to use the DTTEF to reliably assess treatment integrity of DTT sessions, Wightman, Martin, Fazzio, and Arnal (2014) prepared the *Discrete-Trials Teaching Evaluation Form Self-Instructional Manual* (DTTEF-SIM). The purpose of the current study was to evaluate the effectiveness of the DTTEF-SIM with staff from the St.Amant autism programs who supervise the treatment integrity of DTT sessions conducted by staff working with children with ASD.

Materials and Methods

Participants

Ethics approval was obtained from the University of Manitoba Psychology and Sociology Research Ethics Board and St.Amant Research Centre. Participants consisted of six staff members recruited from the St.Amant autism programs. It was made clear that participation was voluntary and would in no way affect their job. Four participants were autism senior tutors and two participants were autism consultants. All participants had experience using DTT. Education level ranged from a bachelor's degree in psychology (all tutors) to a master's in psychology (all consultants). No participants had used the DTTEF prior to the study. All phases of the study were conducted at St.Amant in a private testing room during the day. Baseline and post-training sessions for a pair of participants were conducted during one day and were approximately 30 minutes each. Generalization sessions were conducted approximately one week after this and were 30 minutes long. Follow-up was conducted approximately one month following generalization and took approximately 30 min.

A trained research student at the doctoral level acted as a confederate role-playing an instructor and another trained research student at the doctoral level acted as a confederate role-playing a child with ASD. These individuals had several years of experience as confederates in such roles. Prior to the study, they were required to role-play with 100% accuracy over three sessions. In the study, several confederate/child pairs took part.

Materials

Baseline. A participant received the 20-item DTTEF and a one-page summary on how to use it. The confederate instructor received three scripts, one for each teaching session, indicating how to instruct the session, trial by trial (see Table 1). The teaching sessions across phases consisted of one of three tasks: (a) matching pictures, (b) pointing-to-named-pictures, and (c) motor imitation. The confederate instructor also received teaching materials, which included a data sheet to record the responses of the confederate child, picture flash cards, edibles for reinforcement, and a pen. The confederate child received three scripts, one for each teaching session, indicating how to respond to the instructor, trial by trial (see Table 2).

Training. A participant received the DTTEF-SIM (described below), a computer to practice scoring videos, and a pen.

Post-training. The participant and confederates received the same materials as in Baseline.

High-integrity generalization. Participants received three DTTEFs to score three videos (described later) of a tutor administering DTT to a child with ASD. The videos consisted of 12 trials of the same three teaching tasks from Baseline.

Table 1. Example of Confederate Instructor Script

DTTEF SCORE FORM

COMPONENT **SCORE**

Part II: On Standard Trials, Manage Antecedents	1	2	3	4	5	6	7	8	9	10	11	12
7. Check the data sheet for the arrangement of teaching materials or response to be modeled.	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
8. Secure the child's attention	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9. Present the teaching materials and/or model response	✓	✓	✓	✗	✗	✓	✗	✓	✓	✓	✓	✓
10. Present the correct instruction	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
11. Present Prompts	✗	✗	✗	✗	✗	✗	✓	✓	✓	✓	✓	✓

Part III: On Standard Trials, Manage Consequences & Record Data

Score 12 or 13, NOT both	12. Following a **correct response**, praise & present an additional reinforcer	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	13. Following an **incorrect response**, block gently if possible, remove materials or stop gesturing & show a neutral expression for 2 or 3 seconds												
14a. Record the response immediately/accurately		✓	✗	✓	✗	✗	✓	✓	✓	✓	✓	✓	✓
15a. Allow brief intertrial interval of 3-10 seconds		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	/

Part IV: An Error Correction Trial Following An Error

16. Secure the child's attention												
17. Re-present the materials												
18. Re-present the instruction & prompt immediately to guarantee correct response												
19. Praise only												
14b. Record the response immediately/accurately												
15b. Allow brief intertrial interval of 3-10 seconds												

Part V: Fade Prompts

20. Fade prompts across trials	✗

Follow-up. A participant received the same materials as in Baseline and training. The confederates received the same materials as in Baseline and training. All sessions were videotaped for data collection purposes.

Procedure

We used a concurrent modified multiple-baseline design across a pair of participants, repli-

Table 2. Example of Confederate Child Script

Pointing to Named Pictures Task

Pointing	1	**Pointing**	
Attending/Not attending	A	Attending/Not attending	A
Prompting level	FP	Prompting level	P1
Correct/Error	C	Correct/Error	C
Pointing	2	**Pointing**	9
Attending/Not attending	A	Attending/Not attending	A
Prompting level	FP	Prompting level	(P2)
Correct/Error	C	Correct/Error	E
Pointing	3	**Pointing – ERROR CORRECTION**	9
Attending/Not attending	Tap Table	Attending/Not attending	A
Prompting level	FP	Prompting level	P1
Correct/Error	C	Correct/Error	C
Pointing	4	**Pointing**	10
Attending/Not attending	A	Attending/Not attending	A
Prompting level	P1	Prompting level	(P2)
Correct/Error	C	Correct/Error	E
Pointing	5	**Pointing – ERROR CORRECTION**	10
Attending/Not attending	A	Attending/Not attending	A
Prompting level	(P1)	Prompting level	P1
Correct/Error	E	Correct/Error	C
Pointing – ERROR CORRECTION	5	**Pointing**	11
Attending/Not attending	A	Attending/Not attending	Look down
Prompting level	FP	Prompting level	P1
Correct/Error	C	Correct/Error	C
Pointing	6	**Pointing**	12
Attending/Not attending	A	Attending/Not attending	A
Prompting level	P1	Prompting level	P1
Correct/Error	C	Correct/Error	C
Pointing	7		
Attending/Not attending	A		
Prompting level	P1		
Correct/Error	C		

cated across two more pairs. Each pair of participants was randomly assigned to evaluate one of three levels of treatment integrity during Baseline and Post-training, low, moderate, or high described below. During a generalization phase, participants evaluated videos of a tutor administering DTT to a child with ASD. Finally during a follow-up phase, participants evaluated all three levels of treatment integrity.

Baseline. A participant filled out a background questionnaire that inquired about his or her experience using the DTTEF and DTT. Next, a participant was given one copy of the DTTEF in order to score a live simulated session of the confederate instructor teaching one of three tasks to a confederate role-playing a child with ASD. The teaching tasks were (a) matching pictures (e.g., when a picture of a dog, a house, and a tree are placed in front of a child, and the child is given a picture of the dog, the correct response is to match the pictures of the dog by placing one picture on top of the other); (b) pointing-to-named pictures (when three options are placed on the table in front of the child); and (c) motor imitation (e.g., a teacher would put his or her arms up and say "do this"). The script for each task was divided into 12 teaching trials and 20 DTT components. The scripts for each teaching task were programmed so that the three tasks were taught with a specific level of treatment accuracy, the percentage of correct instructor behaviour during a DTT session. A script was programmed with either (a) low (40%) DTT treatment accuracy, (b) moderate (70%) DTT treatment accuracy, or (c) high (90%) DTT treatment accuracy. The confederate instructor was provided with appropriate stimuli for each of the teaching tasks (described above). Each of the confederates was following a script on how to respond. The confederate instructor's scripts described how to administer each DTT component of each trial in a given session. For example, a script indicated to use an incorrect instruction and incorrect materials in a given trial. The confederate child's with ASD scripts indicated to attend or not attend to the instructor, to respond correctly or incorrectly, and what prompting level was required by the instructor in order to respond.

Across a pair of participants, we evaluated the treatment integrity of the DTT sessions across Baseline (and Post-training) sessions with a programmed level of DTT treatment accuracy of either low (40%), moderate (70%), or high (90%). The pairs of participants were randomly assigned to a DTT treatment accuracy condition. First, a participant received a brief overview of the study and completed the background questionnaire. Next, a participant was given 10 minutes to read a one-page summary of how to score one of three DTT tasks administered to a child with ASD and was given the DTTEF (see Table 3) to review. Once a participant indicated that he/she had finished reading a summary for the teaching task and reviewing the DTTEF, or ten minutes had passed, then he/she attempted to score, using the DTTEF, 12 trials of a live teaching session of the confederate instructor teaching the confederate child. After the first scoring session, a set of abbreviated instructions for a second task was introduced and a participant had 10-minutes to review the instructions and the DTTEF, followed by the attempt to score 12 trials of that session. This was repeated until a participant attempted to score each of three teaching tasks either once (the first participant of a pair) or twice (the second participant of a pair). The order of the tasks that were scored by a participant was random across participants.

Training. A participant received the DTTEF-SIM (available from first author) to study, blank paper, a pen, and a highlighter. The DTTEF-SIM consisted of 18 pages of instruction which included detailed descriptions on correct and incorrect instructor behaviour during HDTT sessions. It also included five training steps corresponding to each of the five parts of the DTTEF (see Table 1), descriptions of the 20 DTT components, 25 study questions, and four practice activities which involved using Parts 1-5 of the DTTEF to evaluate a video demonstration of a confederate instructor using DTT to teach a confederate child with ASD. Throughout the video demonstrations, there were several programmed errors on Components 9, 11, 14a, 14b, 18, and 20. Individuals tend to deliver these components with moderate (e.g., 60%-79%) to poor (e.g., 0%-59%) accuracy after receiving training (Wightman, Yates, Martin, Pear, & Yu, 2013). These components have been noted to be critical elements of DTT (e.g., Carroll et al., 2013; Holcombe, Wolery, & Snyder, 1994). Therefore, it was important to emphasize these components during staff training. When a participant

Table 3. The Discrete-Trials Teaching Evaluation Form (DTTEF) (revised 2012)
(Fazzio, Arnal, & Martin, 2012)

DTTEF

SCORING: = ✔ performed correctly; **X** = performed incorrectly; / = did not apply

COMPONENT **SCORE**

Part I: Prepare to Conduct a Teaching Session

1. Determine the teaching task(s)	
2. Gather the teaching materials	
3. Select at least 3 reinforcers	
4. Arrange the teaching setting	
5. Determine the prompt-fading procedure and the initial fading step	
6. Invite the child to the table and give a reinforcer choice	

Part II: On Standard Trials, Manage Antecedents	1	2	3	4	5	6	7	8	9	10	11	12
7. Check the data sheet for the arrangement of teaching materials or response to be modelled.												
8. Secure the child's attention												
9. Present the teaching materials and/or model response												
10. Present the correct instruction												
11. Present Prompts												

Part III: On Standard Trials, Manage Consequences & Record Data

Score 12 or 13, NOT both	12. Following a **correct response**, praise & present an additional reinforcer												
	13. Following an **incorrect response**, block gently if possible, remove materials or stop gesturing & show a neutral expression for 2 or 3 seconds												
14a. Record the response immediately/accurately													
15a. Allow brief intertrial interval of 3-10 seconds													

Part IV: An Error Correction Trial Following An Error

16. Secure the child's attention												
17. Re-present the materials												
18. Re-present the instruction & prompt immediately to guarantee correct response												
19. Praise only												
14b. Record the response immediately/accurately												
15b. Allow brief intertrial interval of 3-10 seconds												

Part V: Fade Prompts

20. Fade prompts across trials	

had completed studying the manual and each of the practice activities, then the mastery test was administered. It consisted of five questions taken from the DTTEF-SIM, one question from each of Parts 1-5. A participant was required to obtain 100% accuracy on the test in order to proceed to the Post-training phase, If a participant did not receive 100% accuracy, then he/she was required to re-study the material and re-write the question(s) until 100% was achieved.

Post-training. A participant was assessed on the same three tasks, with the same level of DTT treatment accuracy, following the same procedure as during Baseline. A participant was considered to have mastered evaluating the treatment integrity of a task if he/she obtained 80% accuracy or greater on that task. After the post-training assessment, a participant completed a social validity questionnaire.

High-integrity generalization. A participant used the DTTEF to evaluate three videos of an autism tutor teach three tasks, one task per video, to a child with ASD. Participant 5 only scored one generalization video due to scheduling difficulties. The teaching tasks were the same as those used in previous phases. To create the videos used during generalization sessions, the autism tutor was given three data sheets to teach 12 trials of each of the three teaching tasks to the child with ASD. The autism tutor also received a pen, teaching materials (picture flash cards for the pointing-to-named pictures and matching pictures teaching tasks) and edibles to use for reinforcement. The videos showed the autism tutor teaching the child with ASD each of the three tasks with 100% integrity, which was an unplanned result of recruiting an experienced autism tutor, and a high functioning child with ASD.

Follow-up. Approximately seven months after training, four of the six participants were available for a Follow-up assessment. Participants used the DTTEF to evaluate the confederate instructor teach a confederate, who role-played a child with ASD, each of the three teaching tasks, one task per session, as in previous phases. Each teaching task was taught with low (40%), moderate (70%), or high (90%) DTT treatment accuracy. The level of treatment integrity with which a teaching task was taught varied at random across participants.

The dependent variable and inter-observer agreement (IOA). The dependent variable was assessment accuracy using the DTTEF. To calculate the dependent variable, a participant's DTTEF score for a session was compared to the primary researchers DTTEF score for the same session. The scores for each DTT components across trials were compared and session accuracy was calculated by dividing the number of agreements by the number of agreements plus the number of disagreements and then multiplying by 100% (Martin & Pear, 2015).

To obtain IOA, for 30% of the sessions across each phase, a secondary observer who was a trained graduate student also used the DTTEF to score a participant's performance. To calculate IOA, the second observer's DTTEF score was compared to the primary researcher's DTTEF score. IOA was calculated by dividing the number of agreements by the number of agreements plus the number of disagreements and then multiplying by 100% (Martin & Pear, 2015). IOA averaged 92.8% (*SD* = = 5.61%; range: 87.0%–100%).

Procedural integrity (PI). To ensure the procedure was followed correctly, the primary researcher followed a script for each phase of the study. An observer recorded whether the procedure was followed as planned using a checklist that listed the steps that the primary researcher was supposed to follow for a given phase of the study. For a phase, PI was determined by computing the percent of steps that were administered correctly during that session. PI was completed for 78% of the sessions and averaged 100%.

PI was also assessed for the confederate instructor and confederate role-playing a child with ASD for 30% of the sessions. A trained research assistant recorded whether the confederate followed the confederate scripts as intended. Confederate PI was calculated by dividing the number of correct confederate behaviours by the number of correct confederate behaviours plus the number of incorrect confederate behaviours and then multiplying by 100%. Mean confederate instructor PI was 94.2% (*SD* = 3.73%; range: 89.7%–100%) and mean confederate child PI was 97.4% (*SD* = 5.03%; range: 89.2%–100%).

Results

Low DTT Treatment Accuracy Condition

Participant 1 and 2's assessment accuracy improved from Baseline to Post-training (see Figure 1). For Participant 1, improvement was 38.7%. Baseline scores averaged 36.9% (matching pictures, 35.2%; pointing-to-named pictures, 41.4%; motor imitation, 34.1%). Post-training scores averaged 75.6% (matching, 79.1%; pointing, 70.4%; imitation, 77.4%; not meeting mastery on any task. During Generalization assessment accuracy averaged 99.0% (matching, 99.0%; pointing, 99.0%; imitation, 99.0%). During Follow-up, Participant 1 averaged 87.32% (matching, low DTT treatment accuracy, 83.2%; pointing, high DTT treatment accuracy, 88.1%; imitation, moderate DTT treatment accuracy, 91.64%)

During Baseline, Participant 2's assessment accuracy averaged 47.6% across the six tasks (matching, 45.2%, 38.3%; pointing, 44.4%, 36.2%; imitation, 66.4%, 55.1%; see Figure 4). After training, Participant 2's assessment accuracy averaged 83.3% (matching, 80.1%; pointing, 84.9%; imitation, 84.9%; mastery met on all tasks), improving 35.79%. Generalization accuracy was also high (*M* = 99.0%; matching, 99.0%; pointing, 99.0%; imitation, 99.0%). This individual did not participate in the Follow-up sessions due to scheduling conflicts.

Moderate DTT Treatment Accuracy Condition

Participant 5 and 6 also improved from Baseline to Post-training (see Figure 2). For Participant 5, accuracy improved 56.2%. Baseline scores averaged 25.2% (matching, 34.3%; pointing, 22.1%; imitation, 19.3%). At Post-training, accuracy averaged 81.4% (matching, 83.1%; pointing, 76.2%; imitation, 85.1%; mastery met on two tasks). Due to scheduling issues, Participant 5 only evaluated the treatment integrity of one video during Generalization in which he scored 99.0%. During Follow-up accuracy averaged 84.0% (matching, high DTT treatment accuracy, 93.2%; pointing, moderate DTT treatment accuracy, 81.5%; imitation, low DTT treatment accuracy, 77.3%).

Participant 6's Baseline accuracy averaged 50.8% (matching, 57.1%, 41.2%; pointing, 39.3%, 55.1%; imitation, 55.2%, 57%). After training, Participant 6 averaged 89.3% (matching, 88.1%; pointing, 86.3%; imitation, 93.4%; mastery was met on all tasks), improving an average of 38.5%. During Generalization, Participant 6 scored 100% on all tasks. During Follow-up, Participant 6 evaluated the sessions with an average of 87.9% (matching, low DTT treatment accuracy, 83.1%; pointing, moderate DTT treatment accuracy, 88.2%; imitation, high DTT treatment accuracy, 92.4%).

High DTT Treatment Accuracy Condition

Participant 3's assessment of treatment integrity improved from Baseline to Post-training an average of 31.7% (see Figure 3). Participant 3 averaged 66.5% during Baseline (matching, 70.1%; pointing, 73.3%; imitation 56.0%). After training, Participant 3 averaged 98.2% (matching, 99.0%; pointing, 98.3%; imitation, 97.2%), meeting the 80% mastery criterion on all three tasks. During Generalization, Participant 3 averaged of 99% (matching, 99.0%, pointing, 99.0%, imitation, 99.0%). Participant 3 did not participate in the Follow-up Sessions due to scheduling conflicts.

Participant 4's mean assessment accuracy increased from Baseline to Post-training 30.3% (see Figure3). Participant 4 averaged 51.2% during Baseline (matching, 63.4%, 56.0%; pointing, 62.0%, 59.2%; imitation, 32.3%, 34.4%). Post-training scores averaged 81.5% (matching, 74%; pointing, 87.1%; imitation, 83.4%). Thus, Participant 4 met the mastery criterion on two of the three tasks during Post-training. During Generalization Participant 4's assessment accuracy averaged 86.0% (matching; 84.0%, pointing, 85.1%; imitation 88.0%). During Follow-up, assessment accuracy averaged 62.9% (matching, moderate DTT treatment accuracy, 52.0%; pointing, high DTT treatment accuracy, 95.7%; imitation, low DTT treatment accuracy, 41.1%).

Overall, participants averaged 1 hour and 16 minutes to study and master the material in the DTTEF-SIM, ranging from 40 minutes to 1 hour and 55 minutes. For all participants, assessment accuracy during Baseline was low, averaging

47.6% (*SD* = 14.2, range: 19.3%–73.3%), and after training, assessment accuracy increased, averaging 84.7% (*SD* = 8.2, range: 70.4%–99.0%). At Post-training, three of six participants met the mastery criterion of 80% accuracy on all three tasks, two participants met the mastery criterion on two of the three tasks, and one participant did not meet the mastery criterion on any of the three tasks. Accuracy in Generalization was very high for all participants, averaging 96.7% (*SD* = 5.5, range: 84.0%–100%). Finally, in the Follow-up phase, three of the four participants were able to evaluate the treatment integrity of low, moderate, and high DTT treatment conditions with high accuracy (*M* = 77.8%, *SD* = 18.7).

DTTEF Components that Participants Didn't Score

A missed component occurred when a DTT component for a trial was not scored and left blank. As demonstrated in Figure 4, the percentage of missed components was highest during Baseline for all participants except for Participant 5. Following training, the percentage of missed components decreased sizably. During the Generalization phase, the percentage of missed components was very low. During the Follow-up phase, the percentage of missed components also remained low.

The results also demonstrated that some DTTEF Components were missed more frequently than others. Figure 5 demonstrates that Components 14a and 15a were missed a total of 41 times each across participants and phases, followed by Component 20 which was missed 15 times across participants and phases, and then Component 10 which was missed nine times across participants and phases. The remaining DTTEF Components that participants missed occurred at a lower frequency across participants and phases, ranging from 1–6 times.

Social Validity

Participants completed a 7-question social validity form. There were two questions concerning the goals, two questions concerning the procedures, and three questions concerning the effects of the study. The questions were rated on a scale of 1 to 5 (1 = *disagree* and 5 = *agree*). Results suggest that participants found the goals of the study to be important, rating the items an average of 5/5, the procedure to be effective, rating the items an average of 4.88/5, and the training package to be effective, rating the items an average of 4.77/5.

Discussion

Overall, the self-instructional package was found to be effective in improving autism consultants and autism senior tutors accuracy in evaluating the treatment integrity of DTT sessions. The training package took a short amount of time to complete and resulted in an increase in assessment accuracy. Furthermore, positive results were maintained during Generalization sessions one week after training, and also during Follow-up sessions approximately seven months after training.

Several limitations should be noted. During the Generalization phase, the employed autism tutor taught the three DTT tasks with 100% accuracy which may not reflect the range of tutor abilities encountered in the field. The Generalization phase consisted of video files as opposed to live scoring, which would be required in the field. Only four of the six participants were available for the Follow-up sessions and only three of the six participants met the mastery criterion of 80% accuracy on all three tasks at Post-training. This may be due to the fast pace of a live session as there were a large number of missed components in these cases. In comparison to the previous phases, the number of missed components during the Follow-up phase was particularly high for Participant 4 (e.g., up to 48/119). Perhaps a fluency criterion could be used in future studies to improve accuracy at Follow-up and in naturalistic settings. It is also likely that some components are easier to observe and score than others, so further research may want to evaluate which components are more difficult to score and include further training on these components. Finally, participants were scoring DTT between Post-training and Follow-up sessions during regular work hours, so observer drift is possible.

Because this is the first study evaluating the effectiveness of the DTTEF-SIM, future research needs to replicate and extend the results of the current study, and also evaluate other methods used to train individuals to use DTT checklists. Replications should include additional participants in each condition, participants from other agencies, autism tutors with varying levels of experience in a Generalization phase, and children of varying functioning levels in a Generalization phase. Furthermore, since errors on specific components can differentially affect treatment outcomes (e.g., Carroll et al., 2013), recent research has suggested assessing the treatment integrity of individual components as opposed to a global integrity measure (Cook et al., 2015).

In summary, the current study demonstrated that the DTTEF-SIM can be used to teach autism senior tutors and autism consultants to evaluate the treatment integrity of DTT sessions conducted by a confederate instructor and confederate child with ASD, and an autism tutor and child with ASD. The results of this study are important in the application of EIBI and DTT as this training method was time efficient and effective. The current results may enable agencies providing behavioural services to ensure that DTT is being applied consistently and accurately, resulting in positive gains for their clients.

Key Messages From This Article

People with disabilities. The self-instructional package can train staff to evaluate the treatment integrity of discrete-trials teaching sessions to help ensure that clients are receiving effective treatment.

Professionals. The self-instructional package is an effective tool for teaching individuals to evaluate the treatment integrity of discrete-trials teaching sessions.

Policymakers. It is important that staff are administering discrete-trials teaching with integrity in early intervention programs. This paper provides information on an effective method that can be used to train such staff to evaluate treatment integrity with accuracy.

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An Analysis of Training Tasks, Maladaptive Behaviours, and Rates of Task Acquisition Based on Archived Data From an Early Intensive Behavioural Intervention Program

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Abstract

This study, conducted in two parts, evaluated whether the difficulty of the training tasks taught to children enrolled in the St.Amant Autism Early Learning Program matched the learning abilities of the children. In the first part, we demonstrated that: (I) Trained observers could reliably categorize 99 of the 544 tasks of the Assessment of Basic Language and Learning Skills – Revised (ABLLS-R) into individual levels of the Assessment of Basic Learning Abilities – Revised (ABLA-R); and (II) Autism consultants from the St.Amant autism programs averaged 90.5% agreement that those ABLLS-R tasks were taught at the categorized ABLA-R levels. In the second part, we examined archived data for 14 children from the St.Amant Autism Early Learning Program. We found that: (III) 81% of each child's ABLLS-R training tasks were mismatched to each child's highest-passed ABLA-R level; (IV) 61% of their assessments of maladaptive behaviours had a score indicative of challenging behaviours; and (V) The children's rates of acquisition of new training tasks were lower for mismatched tasks than for matched tasks. This study provides valuable information for service providers to improve early intensive behavioural intervention programs for children with autism spectrum disorder.

Research has established early intensive behavioural intervention (EIBI) as the treatment of choice for young children with autism spectrum disorder (ASD) (Martin & Pear, 2015; Matson & Konst, 2013; Matson & Smith, 2008; Matson & Sturmey, 2011). A commonly used curriculum guide in EIBI programs for children with ASD is the Assessment of Basic Language and Learning Skills-Revised (ABLLS-R; Partington, 2006), which is used as an assessment, a curriculum guide, and skills tracking system. Table 1 illustrates the types of skills and descriptions that can be found in the ABLLS-R manual.

Another assessment that is used in some EIBI programs with children with ASD is the Assessment of Basic Learning Abilities (ABLA; Kerr et al., 1977), which assesses a testee's ability to learn six discriminations, referred to as levels. The ABLA was revised in 2011 to include a new Level 5 task, and is now referred to as the Assessment of Basic Learning Abilities-Revised, or ABLA-R (DeWiele, Martin, Martin, Yu, & Thomson, 2011; see Table 2). Research on the original ABLA and ABLA-R has demonstrat-

Table 1. Examples of Tasks From the ABLLS-R Identified for the Cooperation and Reinforcer Effectiveness Skill (A)

Task	*Task Name*	*Task Objective*	*Question*	*Examples*
A1	Take reinforcer when offered	When offered a known reinforcing item or activity, the student will take/use the item or activity.	When you hold out and offer a known reinforcer, will the student take the reinforcer?	M & M taken and eaten
A2	Take a reinforcer from two choices of items	When offered one reinforcing item or activity and another non-reinforcing item or activity, the student will select the reinforcing item or activity.	When you hold out and offer a reinforcer and a non-reinforcing item, will the student take the reinforcer?	M & M vs. shoe, will take M & M
A3	Look at a non-reinforcing item	Student will look and track changes in location of a non-reinforcing item presented by an instructor.	If you hold up a non-reinforcing item, will the student look at it and watch it as you move it to different locations in front of the student?	When you hold up a shoe and ask the student to look at the shoe, student will look at it and watch it as you move it to a variety of positions in front of him (e.g., up/down/left/right)
A4	Take common object when offered	When offered a common object, the student will take the item.	When you hold out and offer an item, will the student take the object?	When you hold out a shoe, student will take it

Note: Reprinted with permission from "The Assessment of Basic Language and Learning Skills – Revised (ABLLS-R protocol)" by J. W. Partington, 2006, Pleasant Hill, CA: Behavior Analysts, Inc.

ed, with persons with intellectual disabilities (ID) and children with ASD, that: (a) The six levels are ordered in difficulty from Level 1 (easiest) to Level 6 (most difficult); (b) training tasks can be analyzed according to the highest ABLA level needed to perform them; and (c) ABLA test performance can be used to match the learning ability of participants to training tasks (DeWiele & Martin, 1996; Martin, Thorsteinsson, Yu, Martin, & Vause, 2008; Murphy, Martin, & Yu, 2014; Schwartzman et al., 2009; Yu, Martin, Vause, & Martin, 2015). Research has also demonstrated, with persons with ID, that the ABLA difficulty of training tasks that are matched to a client's highest-passed ABLA level results in fewer aberrant behaviours than tasks that are mismatched to that client's highest-passed ABLA level (Vause et al., 2000; Vause, Martin, & Yu, 1999). Does this latter finding hold for children with ASD? Given the increasing prevalence of ASD and the limited availability of qualified service providers, it is critical that we evaluate whether children's training curricula are designed to ensure rapid acquisition of a variety of skills while decreasing levels of aberrant behaviours.

To address this question, research was conducted at the St.Amant Autism Early Learning Program, a large community-based EIBI program based in Winnipeg. The program offers up to 3 years of EIBI services to children with ASD, and serves a large number of children with ASD across Manitoba. This program was selected as it uses both the ABLLS-R and ABLA-R. These assessments are conducted on a 6-month or yearly basis for all children to measure skill acquisition, learning ability, and challenging behaviours.

Table 2. A Description of the ABLA and ABLA-R Levels and the Types of Discriminations Required

ABLA Level	*Test Task*	*Everyday Examples*
Level 1 Imitation	When given a piece of foam, can the student imitate the teacher placing the foam into a container?	Children playing Follow-the-Leader.
Level 2 Position Discrimination	When presented with a yellow can and a red box in a stable position, can a student consistently place a piece of foam into the container on the left?	Turning on the cold (vs. the hot) water tap.
Level 3 Visual Discrimination	When presented with a yellow can and a red box in randomly alternated left-right positions, can a student consistently place a piece of foam into the can?	Locating own printed name on blackboard when placed in different positions with other names.
Level 4 Visual Identity Match-to-Sample Discrimination	When presented with a yellow can and a red box in randomly alternated left-right positions, can a student consistently place a small yellow cylinder into the can, and a small red cube into the box?	Sorting socks into pairs.
Original Level 5 Auditory Discrimination	When presented with a yellow can and a red box (in fixed positions), can a student consistently place a piece of foam in the appropriate container when the teacher randomly says, "red box" or "yellow can"?	Responding appropriately to requests such as, "fork" vs. "spoon," when both are in a consistent location on either side of a plate.
New Level 5 Visual Non-Identity Match-to-Sample Discrimination	When presented with a yellow can and a red box in randomly alternated left-right positions, can a student consistently place a purple-coloured piece of wood shaped like the word *Can* into the can, and a piece of silver-coloured wood shaped like the word *BOX* into the box?	Placing a cup with a saucer.
Level 6 Auditory-Visual Combined Discrimination	When presented with a yellow can and a red box in randomly alternated left-right positions, can a student consistently place a piece of foam into the correct container when the teacher requests either "red box" or "yellow can"?	Responding appropriately to requests such as, "pass the salt" vs. "pass the pepper" when the salt and pepper shakers are in different places on the table from meal to meal.

Note: Reprinted with permission from "The Kerr Meyerson Assessment of Basic Learning Abilities Revised: A Self-Instructional Manual (second edition)" by L. DeWiele, G. L. Martin, T. Martin, C.T. Yu, and K. Thomson, 2011, Winnipeg, MB: St.Amant Research Centre.

To evaluate whether the difficulty of the training tasks taught to children enrolled in the St.Amant Autism Early Learning Program matched the learning abilities of the children, five different questions were examined in two parts. In the first part, two questions were examined: (I) Can observers who are knowledgeable about the ABLA-R reliably categorize each of the 544 tasks of the ABLLS-R into an ABLA-R level per task? and (II) For the ABLLS-R tasks that were reliably categorized into ABLA-R levels, do autism consultants from the St.Amant autism programs typically teach each of those ABLLS-R tasks at the ABLA-R levels into which they have been categorized? Information gathered in the first part allowed us to proceed with the second part of the study. In the second part, we examined three additional questions: (III) Based on archived data for a sample of children from the St.Amant Autism Early Learning Program, to what extent did the ABLA-R difficulty level of ABLLS-R training tasks match the learning abilities of the children as assessed by the ABLA-R? (IV) For those children, was there a relation between the proportions of training tasks mismatched to the children's highest-passed ABLA-R levels and their maladaptive behaviour scores? and (V) For those children, was there correspondence between the children's proportions of mismatched tasks and their rates of acquisition of new training tasks?

PART I

Question I: Can the 544 Training Tasks of the ABLLS-R be Categorized into Assessment Levels of the ABLA-R?

Materials and Methods

To answer this question, three undergraduate psychology students were recruited and given forms and instructions to follow for the categorization of each of the 544 tasks. For each task, they were asked to read the task description as outlined in the ABLLS-R manual, compare the task to the ABLA-R level descriptions that were provided, and identify whether the task was categorizable according to one of the ABLA-R levels, or whether the task was non-categorizable (Roy-Wsiaki, 2016). A categorization was defined as an agreement if the observers assigned the same ABLA-R level to a task; otherwise, the categorization was defined as a disagreement. In addition, a task was labelled as categorizable if it was found to closely approximate one of the six ABLA-R levels; otherwise, the task was labelled as non-categorizable. With this process, we progressively eliminated ABLLS-R tasks that did not closely match any of the ABLA-R levels, eliminated ABLLS-R tasks that could not be reliably categorized into one of the ABLA-R levels, and finally, identified ABLLS-R tasks that could be reliably categorized according to the highest ABLA-R level needed to perform them.

Results

Overall, 439 tasks were identified as non-categorizable and 99 tasks were agreed categorizable with substantial agreement based on a kappa coefficient of 0.7601 (Cohen, 1968). Six tasks were used for training purposes, and therefore not included in the categorizations. All 99 tasks agreed categorizable were reliably assigned a corresponding ABLA-R level, with 35 tasks categorized as Level 1, five tasks categorized as Level 2, three tasks categorized as Level 3, 24 tasks categorized as Level 4, 13 tasks categorized as Level 5, and 19 tasks categorized as Level 6. Table 3 lists the 99 ABLLS-R tasks categorized according to ABLA-R levels. With these 99 tasks, we proceeded with the second question.

Question II: For ABLLS-R Tasks Categorized at ABLA-R Levels, Are They Typically Taught at Those Levels by St.Amant Staff?

Materials and Methods

To address this question, we created the Fidelity of Training Programs Survey. From the 99 categorized ABLLS-R tasks, we randomly selected two ABLLS-R tasks from those categorized at ABLA-R Level 1, two tasks from those categorized at Level 2, and so on for the ABLLS-R tasks at each ABLA-R level, for a total of 12 tasks. We then created a survey question for each task, with the objective of evaluating whether autism consultants who work for the St.Amant autism programs develop training programs based on the guidelines in the ABLLS-R manual. Each question prompted the autism consultants to review an ABLLS-R task that was categorized into an ABLA-R level, and to answer "Yes" or "No," as to whether they developed their programs based on the descriptions (or guidelines) provided. The descriptions for each ABLLS-R task (i.e., task objective, question, example) were obtained from the ABLLS-R manual. For a sample of two of the 12 survey questions, see Figure 1 on page 34.

The survey was administered at St.Amant, during an autism programs' team meeting. On that day, 16 of the 18 autism consultants were present. Autism consultants who wished to

Table 3. ABLLS-R Task Categorizations With Substantial Agreement on the ABLA-R Level of Each Task Based on Kappa

ABLA-R level	*Categorized ABLLS-R tasks*											
Level 1	B20	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11
	D12	D13	D14	D15	D16	D17	D18	D19	D20	D21	D22	D23
	D24	D26	D27	L8	L9	N6	R1	R3	T3	Z26	Z28	
Level 2	B12	C10	C11	Z2	Z6							
Level 3	A3	B21	Q9									
Level 4	B1	B2	B3	B4	B5	B6	B7	B8	B9	B13	B15	C55
	Q1	Q2	Q6	Q8	T2	T4	Z3	Z4	Z5	Z7	Z20	Z22
Level 5	B10	B11	B16	B17	B18	B19	B23	B24	C24	C36	C56	Q5
	Z23											
Level 6	C12	C13	C14	C16	C17	C32	C35	C40	C45	C47	C48	
	N8	Q3	R9	R10	R11	R12	R13	R15				

complete the survey and who had provided their consent to participate were given 15 minutes to complete the survey. Procedures were implemented to ensure that completion of the survey remained voluntary and anonymous.

Results

A total of 14 surveys were completed, and two surveys were returned incomplete. For each question on the survey, a checked "Yes" was interpreted as an agreement with the question, and a checked "No" was interpreted as a disagreement with the question. Summarized data demonstrated an average of 90.5% agreement across autism consultants, with percent agreement ranging from 75% to 100% (see Table 4 on page 35).

These results indicate that in general, training programs were developed based on the guidelines in the ABLLS-R manual, and more specifically, there was an average of 90.5% agreement that the categorized ABLLS-R tasks were taught at their respective ABLA-R levels.

PART II

Question III: What Percentage of Training Tasks Were Taught At, Below, and Above Each Child's Highest-Passed ABLA-R Level?

Materials and Methods

To answer this question, as well as the next two questions, existing client data was obtained from the St.Amant Autism Early Learning Program archival database for 14 children who met the inclusion criteria. Inclusion criteria involved available archived assessment data for the ABLA-R and the Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996), as well as the ABLLS-R training task databases. Assessment periods selected for this study were limited to Year 1, Year 1.5, and Year 2, such that the children who had all required data for any of these three assessment periods met the inclusion criteria.

Fidelity of Training Programs Survey

BACKGROUND: In an earlier phase of my study, reliability assessments were conducted to categorize ABLLS-R tasks into ABLA-R levels. We were successful in categorizing 99 ABLLS-R tasks.

PURPOSE: The purpose of this survey is to assess whether autism consultants develop training programs based on the guidelines in the ABLLS-R manual.

INSTRUCTIONS: Please read each question and ABLLS-R task description carefully. For each question, check either YES or NO.

2. For the ABLLS-R task below, do you typically develop a program to teach the task as outlined in the description below, and therefore as an ABLA-R Level 1 task? Meaning that the desired behaviour is modeled before the response occurs, and involves an imitation.

YES __________ NO __________

Task	Task Name	Task Objective	Question	Example
D4	Imitation of leg and foot movements	Upon request, student will imitate a gross motor activity involving foot and leg movements.	Will the student imitate a gross motor action involving foot and leg movements when asked to "Do this"?	Stomp foot

8. For the ABLLS-R task below, do you typically develop a program to teach the task as outlined in the description below, and therefore as an ABLA-R Level 4 task? Meaning that the task involves visually matching something to something else in the environment on the basis that the two matching items are the same on at least one physical dimension.

YES __________ NO __________

Task	Task Name	Task Objective	Question	Example
Q8	Match individual letters to letters on word card	The student will be able to match individual letters to the letters on cards with single 5 letters words.	Can the student match individual letters to the letters on cards with single 5 letter words?	Given a word card with the word "train," the student will match individual letter cards to the letters on the word card

Figure 1. The instructions and two questions (#2 and #8) from the Fidelity of Training Programs Survey that contains 12 questions. Task descriptions adapted with permission from "The Assessment of Basic Language and Learning Skills-Revised (ABLLS-R protocol)" by J. W. Partington, 2006, Pleasant Hill, CA: Behavior Analysts, Inc.

Table 4. Individual and Summarized Results of Survey Completed by Autism Consultants From the St.Amant Autism Programs

	Survey Question												*Agreement*	
Participant	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*Number*	*Percent*
1	1	1	1	1	1	1	1	1	1	1	1	1	12	100%
2	1	1	1	1	1	1	1	1	1	1	1	1	12	100%
3	1	1	1	1	1	1	1	1	1	1	1	1	12	100%
4	1	1	1	1	1	1	1	1	1	1	1	1	12	100%
5	1	1	1	1	1	1	1	1	1	1	1	1	12	100%
6	1	1	1	1	1	1	1	1	1	1	1	0	11	92%
7	1	1	1	1	1	1	1	1	1	1	0	1	11	92%
8	1	1	1	1	1	0	1	1	1	1	1	1	11	92%
9	1	1	1	1	1	1	1	1	1	1	1	0	11	92%
10	1	1	1	1	1	1	1	0	0	1	1	1	10	83%
11	1	1	1	1	1	0	1	1	1	1	1	0	10	83%
12	1	1	1	1		1	1		1	1	1	1	10	83%
13	1	1				1	1	1	1	1	1	1	9	75%
14	0	1	1	0	1	0	1	1	1	1	1	1	9	75%
Total average													11	90.5%

Note: 1 = "Yes" or agreement, and indicates that the ABLLS-R task described in the survey question was taught at its categorized ABLA-R level; 0 = "No" or disagreement, and indicates that the ABLLS-R task described in the survey question was not taught at its categorized ABLA-R level; blank = no response.

For all those 14 children, we analyzed each of their archived data for any given assessment period in the following manner. First, we compared each child's ABLA-R assessments to his or her ABLLS-R training task database, to ensure the dates for a particular assessment period corresponded to tasks that were taught within 1 month prior to the assessment dates.

Second, we identified within the 1 month of training task data, those tasks that corresponded to the 99 ABLLS-R tasks that were reliably categorized according to the highest ABLA-R level needed to perform them, in Part I. This provided a list of training tasks and their respective ABLA-R levels.

Third, we compared this list to the ABLA-R score for that assessment period, to identify the training tasks that were *at* the child's highest-passed ABLA-R level, *below* that ABLA-R level, and *above* that ABLA-R level. A task at the child's highest-passed ABLA-R level signified that the task's categorized ABLA-R level was identical to the child's highest-passed ABLA-R level, and was therefore labelled a "match." A task below or above the child's highest-passed ABLA-R level was labelled a "mismatch."

Fourth, we determined the percentage of tasks taught at, below, and above each child's highest-passed ABLA-R level by calculating the number of tasks matched or mismatched divided by the total number of tasks. For specific mismatched percentages, we divided the number of tasks mismatched below or mismatched above by the total number of mismatched tasks.

Results

Data was analyzed for a total of 31 assessment periods and 1006 tasks (including each task's respective exemplars). The number of tasks per child ranged from 6 to 84, with an average of 32 tasks per child. Overall, results demonstrated that an average of 19% of tasks were matched and 81% of tasks were mismatched to the children's highest-passed ABLA-R levels. Of those mismatched tasks, 64% were mismatched below the children's highest-passed ABLA-R levels, and 36% were mismatched above the children's highest-passed ABLA-R levels. Table 5 presents each child's specific percentages.

Question IV: What Was the Relationship Between the Proportions of Matched Versus Mismatched Tasks and Maladaptive Behaviour Scores?

Materials and Methods

Children's maladaptive behaviour scores reflected the scores of the SIB-R which is a comprehensive, norm-referenced assessment of 14 areas of adaptive behaviours and eight areas of maladaptive behaviours. For the purposes of this study, the General Maladaptive Index (GMI) composite score was chosen as the measure of maladaptive behaviour for each child.

For all 14 children and across their 31 assessment periods, we obtained an SIB-R GMI score. We then referred to the SIB-R Maladaptive Behavior Indexes Profile to assign a corresponding label to each score (i.e., Normal, Marginally serious, Moderately serious, Serious, or Very serious). Any score other than what was considered normal was recognized as a score representative of maladaptive behaviours. Finally, we compared the children's maladaptive behaviour scores to their proportions of matched and mismatched tasks (Table 6).

Results

Across 31 SIB-R assessments, 12 assessments (39%) demonstrated normal behaviour scores and 19 assessments (61%) demonstrated maladaptive behaviour scores. A correlation measure was used to evaluate whether there was a relation between the proportions of training tasks mismatched to the children's highest-passed ABLA-R levels and their maladaptive behaviour scores. Based on previous research (e.g., Vause et al., 1999), my hypothesis was that more maladaptive behaviours would be found for children who were presented with a larger number of mismatched tasks versus tasks matched to their highest-passed ABLA-R level. A Pearson product-moment correlation was tested between average percentages of matched tasks and average maladaptive behaviour scores across 12 children (for whom a percentage of tasks matched their ABLA-R level). Each child's average percentage of tasks or average maladaptive behaviour score was calculated by averaging the data across his or her respective assessment periods. Results demonstrated that the relationship of average maladaptive behaviour scores with matched tasks (r = -.436, p = .157) was not statistically significant at a p value of .05, possibly due to sample size restrictions. However, this p value suggests that children may engage in fewer or less intensive maladaptive behaviours when presented with tasks that match their highest-passed ABLA-R level. The same test was conducted between average percentages of mismatched tasks and average maladaptive behaviour scores across all 14 children. Results for mismatched tasks (r = -.047, p = .873) also lacked statistical significance at a p value of .05. Nevertheless, 11 of the 14 children demonstrated a varying degree of maladaptive behaviour, and these behaviours may very well interfere with the children's ability to learn and acquire valuable skills. See Table 6 on page 38 for each child's respective maladaptive behaviour scores.

Question V: What Was the Relationship Between the Proportions of Matched Versus Mismatched Tasks and Rates of Task Acquisition?

Materials and Methods

Trial-by-trial data is consistently collected for ABLLS-R training tasks taught during instruction sessions in the St.Amant autism programs. Consequently, the fifth question was examined by using a trials-to-criterion measure. An average rate of training task acquisition was obtained by calculating, for each child, the total number of trials required to meet the mastery criterion

Table 5. Percentage of Tasks At, Below, and Above Each Child's Highest-Passed ABLA-R Level

				Percentage of Tasks			
Participant	*Assessment period*	*ABLA-R level*	*Number of tasks*	*Matched*	*Mismatched*	*Mismatched below*	*Mismatched above*
1	1	6	38	0%	100%	100%	0%
	2	6	14	43%	57%	100%	0%
2	1	3	19	0%	100%	58%	42%
	1.5	6	50	0%	100%	100%	0%
	2	6	49	22%	78%	100%	0%
3	1	4	20	50%	50%	30%	70%
4	1	2	17	0%	100%	29%	71%
	1.5	2	19	0%	100%	58%	42%
	2	3	21	5%	95%	20%	80%
5	1	1	22	68%	32%	0%	100%
	2	3	35	3%	97%	71%	29%
6	1	4	84	49%	51%	65%	35%
	1.5	4	35	11%	89%	55%	45%
	2	6	55	5%	95%	100%	0%
7	1	4	74	1%	99%	25%	75%
	2	6	36	17%	83%	100%	0%
8	1	3	58	0%	100%	36%	64%
	1.5	3	26	0%	100%	50%	50%
	2	3	26	0%	100%	69%	31%
9	1	4	31	39%	61%	32%	68%
	1.5	6	33	0%	100%	100%	0%
	2	6	10	30%	70%	100%	0%
10	1	4	42	12%	88%	51%	49%
	1.5	4	24	21%	79%	58%	42%
	2	4	29	14%	86%	96%	4%
11	1.5	4	6	0%	100%	50%	50%
12	1	4	18	22%	78%	79%	21%
13	1	4	42	52%	48%	80%	20%
	2	4	38	45%	55%	90%	10%
14	1	4	23	52%	48%	27%	73%
	2	4	12	42%	58%	57%	43%
Total			1006				
Average			32	19%	81%	64%	36%

Note: The children's original test scores were based on the ABLA.

Table 6. Summary of Percentage of Matched and Mismatched ABLLS-R Tasks With SIB-R GMI Scores and Profiles Across Assessment Periods

		Percentage of Tasks					
Participant	*Assessment period*	*Matched*	*Mismatched*	*Mismatched below*	*Mismatched above*	*SIB-R GMI score*	*Index profile*
1	1	0%	100%	100%	0%	-4	Normal
	2	43%	57%	100%	0%	-21	Moderately serious
2	1	0%	100%	58%	42%	-4	Normal
	1.5	0%	100%	100%	0%	-3	Normal
	2	22%	78%	100%	0%	-4	Normal
3	1	50%	50%	30%	70%	-14	Marginally serious
4	1	0%	100%	29%	71%	-11	Marginally serious
	1.5	0%	100%	58%	42%	-26	Moderately serious
	2	5%	95%	20%	80%	-33	Serious
5	1	68%	32%	0%	100%	-32	Serious
	2	3%	97%	71%	29%	-24	Moderately serious
6	1	49%	51%	65%	35%	-18	Marginally serious
	1.5	11%	89%	55%	45%	-17	Marginally serious
	2	5%	95%	100%	0%	-15	Marginally serious
7	1	1%	99%	25%	75%	1	Normal
	2	17%	83%	100%	0%	-6	Normal
8	1	0%	100%	36%	64%	-35	Serious
	1.5	0%	100%	50%	50%	-9	Normal
	2	0%	100%	69%	31%	-32	Serious
9	1	39%	61%	32%	68%	-16	Marginally serious
	1.5	0%	100%	100%	0%	-12	Marginally serious
	2	30%	70%	100%	0%	-8	Normal
10	1	12%	88%	51%	49%	-6	Normal
	1.5	21%	79%	58%	42%	-9	Normal
	2	14%	86%	96%	4%	-10	Normal
11	1.5	0%	100%	50%	50%	-52	Very serious
12	1	22%	78%	79%	21%	-18	Marginally serious
13	1	52%	48%	80%	20%	-2	Normal
	2	45%	55%	90%	10%	-20	Marginally serious
14	1	52%	48%	27%	73%	-42	Very serious
	2	42%	58%	57%	43%	-38	Serious
Average		19%	81%	64%	36%	-17	Marginally serious

Note: GMI = General Maladaptive Index. The maladaptive behaviour index values are interpreted in the SIB-R as follows: +10 to -10 = Normal; -11 to -20 = Marginally serious; -21 to -30 = Moderately serious; -31 to -40 = Serious; -41 and below = Very serious.

(i.e., criterion that demonstrates understanding of the task) divided by the total number of tasks.

For all 14 children and across 30 assessment periods, we obtained trials-to-criterion data for a total of 462 mastered tasks (including each task's respective exemplars) corresponding to the 99 ABLLS-R tasks from Part I. With this trials-to-criterion data, we calculated the number of trials required to achieve the mastery criterion for each task. For each child, we then proceeded in calculating the average number of trials required to achieve the mastery criterion for tasks that matched the child's highest-passed ABLA-R level, and tasks that were a mismatch below and above the child's ABLA-R level. The average number of trials was calculated by dividing the total number of trials, corresponding to tasks matched, mismatched below, or mismatched above the child's highest-passed ABLA-R level, by the total number of tasks.

Results

Results demonstrated that children required an average of 25 trials to master tasks matched to their highest-passed ABLA-R level, and 42 trials to master tasks mismatched to their ABLA-R level. More specifically, children required an average of 47 trials to master tasks mismatched below their highest-passed ABLA-R level, and 34 trials to master tasks mismatched above their ABLA-R level. A paired-samples *t*-test was conducted to compare average rates of acquisition for matched versus mismatched tasks (n = 9). Results demonstrated that there was no significant difference in rates of acquisition between matched tasks ($M = 32.77$, $SD = 32.65$) and mismatched tasks ($M = 52.73$, $SD = 36.95$); $t(8) = 1.267$, $p = .241$. Again, this may have been due to the limited sample of data. However, based on the average rates of acquisition reported above, lower rates of acquisition were found for mismatched tasks, and overall, children in this sample were presented with a larger number of tasks that were mismatched to their ability levels. Table 7 on page 40 presents the children's individual rates of acquisition.

Discussion

In Part I of this study, we first examined whether observers who are knowledgeable about the ABLA-R could reliably categorize each of the tasks of the ABLLS-R into an ABLA-R level per task. Observers agreed that a total of 439 tasks were non-categorizable, meaning that those tasks did not fit any of the predetermined ABLA-R guidelines, and a total of 99 tasks were categorizable. These categorizations were confirmed reliable with substantial agreement based on Kappa.

This study represents the first attempt to reliably categorize the 544 ABLLS-R training tasks according to an ABLA-R level per task. The finding that 99 tasks were agreed upon by observers as categorizable represents a contribution of practical significance, given that EIBI programs often use the ABLLS-R as a skills tracking system and curriculum guide, and some use the ABLA-R as a learning assessment tool. When comparing the list of 99 categorized ABLLS-R tasks to the ABLA-R level descriptions, staff working with children with ASD may find it easier to develop programs that are appropriate for the children's learning ability levels, and thereby reduce potential frustration or number of trials required to master tasks or skills.

A potential limitation is that although 99 ABLLS-R tasks were reliably categorized according to the highest ABLA-R level needed to perform them, 439 tasks were left non-categorizable. Therefore, staff working with children with ASD may be limited in the comparisons they are able to make between ABLLS-R tasks and ABLA-R levels for any given child. Future research might examine the use of additional possible ABLA-R levels (e.g., auditory-auditory identity matching; Harapiak, Martin, & Yu, 1999; Marion et al., 2003) to categorize the ABLLS-R tasks, so that more tasks may be reliably categorized into ABLA-R levels.

We then examined whether autism consultants from the St.Amant autism programs typically taught a random sample of those 99 ABLLS-R tasks at the ABLA-R levels into which they were categorized. Results indicated there was an average agreement of 90.5% that the categorized ABLLS-R tasks were taught at their respective ABLA-R levels. This outcome contributes important information with regards to EIBI and evaluations of procedural fidelity, as it is often difficult in large EIBI meta-analysis studies to confirm that treatment and other procedures are delivered as described.

Table 7. Average Rates of Acquisition for Tasks Matched, Mismatched Below, and Mismatched Above the Children's Highest-Passed ABLA-R Levels

		Average Rate of Acquisition		
Participant	Assessment period	Tasks matched to ABLA level	Tasks below ABLA level	Tasks above ABLA level
1	1		18	
	2	8	33	
2	1		22	31
	1.5			
	2	6	74	
3	1	26	29	
4	1		4	3
	1.5		25	60
	2			39
5	1			31
	2		178	
6	1	3	15	39
	1.5		38	168
	2		30	
7	1		38	11
	2		29	
8	1		208	15
	1.5		100	
	2		95	19
9	1	14	32	43
	1.5		30	
	2		29	
10	1	73	52	9
	1.5	16	70	67
	2	113	64	
11	1.5		85	46
12	1	96	61	
13	1	44	15	
	2	79	80	5
14	1	20		1
	2		48	485

Although the autism consultants showed very high agreement that the 12 ABLLS-R tasks on the survey were taught at their respective ABLA-R levels, future research might examine whether autism consultants follow the ABLLS-R guidelines for all 99 categorized tasks. Future research might also conduct a more thorough procedural fidelity evaluation, by obtaining and comparing specific training programs to their corresponding ABLLS-R task descriptions. Furthermore, future research might examine the extent to which autism tutors follow program procedures as written by the autism consultants.

In Part II of this study, we examined to what extent the ABLA-R difficulty level of ABLLS-R training tasks matched the learning abilities of the children as assessed by the ABLA-R. Results demonstrated that an average of 19% of tasks were matched and 81% of tasks were mismatched to the children's highest-passed ABLA-R levels. Of those mismatched tasks, 64% were mismatched below the children's ABLA-R levels, and 36% were mismatched above the children's ABLA-R levels. Given that children in these types of programs generally obtain services for a limited amount of years, it is crucial that staff quickly identify and develop training programs that are appropriate for a child's ability level, at any given point in time. Doing so may increase the effectiveness of instruction sessions, and in turn, children may learn at a faster rate a larger number of skills that are required for daily functioning and integration into school and other occupational areas. Future research might examine whether additional staff training on the use of assessments (e.g., the ABLLS-R and the ABLA-R) may improve the development of training programs to ensure a better match of training tasks to the children's ability levels.

We then examined whether there was a relation between the proportions of training tasks mismatched to the children's highest-passed ABLA-R levels and their maladaptive behaviour scores. Overall results demonstrated that 12 assessments (39%) demonstrated normal behaviour scores and 19 assessments (61%) demonstrated maladaptive behaviour scores. A limitation was that it was not possible to determine with certainty that the SIB-R scores indicative of maladaptive behaviours were directly related to the presentation of mismatched tasks. First, there was no statistically significant relationship found between the maladaptive behaviour scores and the proportions of tasks mismatched to the children's ABLA-R levels. Second, given that the maladaptive behaviour scores were based on archived data, there were no direct observations to demonstrate that the presentation of mismatched tasks caused the increase in maladaptive behaviours for these children. It is also important to note that because the SIB-R is generally completed by parents or legal guardians based on their own perceptions of their child's behaviour, the results may lack accuracy and they may be influenced by other events or situations that may have occurred near the assessment dates. Consequently, future studies may look at conducting direct observations or identifying a more objective measure of maladaptive behaviour (e.g., a functional analysis or functional assessment conducted within a particular period).

Finally, we examined whether there was correspondence between the children's proportions of mismatched tasks and their rates of acquisition of new training tasks. Results demonstrated that children required an average of 25 trials to master tasks matched to their highest-passed ABLA-R level, and 42 trials to master tasks mismatched to their ABLA-R level. More specifically, children required an average of 47 trials to master tasks mismatched below their ABLA-R level, and 34 trials to master tasks mismatched above their ABLA-R level; perhaps this particular difference was due to boredom or lack of motivation with the larger proportions of tasks that are considered too easy (note that an average of 64% of mismatched tasks were mismatched below the children's highest-passed ABLA-R levels). Despite the lack of a statistically significant difference in rates of acquisition between matched and mismatched tasks, these results contribute beneficial information to the EIBI literature, and more specifically, to staff working with children enrolled in large EIBI programs.

The results of Parts I and II of this study expand the current research on children with ASD, the ABLA-R and the ABLLS-R, with the objective of improving individualized training procedures and curricula currently used in EIBI programs for children with ASD. Given the increasing prevalence of ASD, the limited amount of funding, and the growing waitlists for families with children with ASD, these studies contribute valuable information that may benefit both service providers and families receiving services.

Key Messages From This Article

People with disabilities. It is important that you receive services and treatments that match your specific needs and abilities, to promote your opportunities to quickly learn and be successful, with less frustration.

Professionals. You have a critical role in helping people with disabilities. It is necessary for you to ensure that a person's training tasks correspond to their learning ability. One way to do this is by measuring what a person is already able to do, and then using this information to find training tasks and activities that are a good match for that person.

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Apprentissage de l'orthographe lexicale en français chez des jeunes élèves ayant un trouble du spectre de l'autisme : profils et recommandations

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writing assessment

Résumé

Apprendre à orthographier les mots en français représente un défi pour plusieurs élèves puisque cela exige des connaissances des correspondances entre les lettres et les sons, mais aussi la mémorisation de l'écriture des mots. Cette étude examine le développement de l'orthographe lexicale chez 15 élèves de cinq à sept ans ayant un trouble du spectre de l'autisme. Ces élèves fréquentent des classes spéciales dans lesquelles les enseignantes adoptent des pratiques pédagogiques semblables à celles de classes ordinaires en ce qui a trait à l'écrit. Cette étude vise à alimenter les connaissances sur le potentiel de ces élèves à traiter la langue écrite. Elle vise également à contribuer à la réflexion sur les voies favorisant leur réussite scolaire et éducative. Des données ont été recueillies à partir d'une tâche d'écriture sous dictée de cinq mots et d'une phrase administrée à trois moments au cours d'une année scolaire. Cette tâche comprend des mots ayant des caractéristiques linguistiques différentes, permettant ainsi d'observer diverses habiletés et connaissances des élèves. Des analyses s'appuyant sur le modèle des « préoccupations du jeune scripteur » ont été menées afin de mettre en lumière leurs préoccupations visuographiques, sémiographiques, alphabétiques et orthographiques.[1] *Les résultats indiquent que ces élèves manifestent des préoccupations différentes entre eux. De plus, chaque élève montre des préoccupations différentes entre les trois passations de la tâche, ce qui indique qu'ils développent tous des connaissances nouvelles en cours d'année. Ceci rappelle le développement de l'orthographe chez des jeunes scripteurs neurotypiques fréquentant les classes ordinaires.*

Young Students With Autism Spectrum Disorder Learning How to Spell in French: Profiles and Recommendations

Abstract

Learning to spell in French is a challenge for many students because they need knowledge of letter-sound correspondences and also they need to memorize written words in order to write them properly. This study examines the development of spelling among 15 students with autism spectrum disorder

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[1] Celles-ci rejoignent les caractéristiques de mots en français. Les mots ont un aspect visuel, ils ont un sens, ils utilisent des lettres pour traduire des sons et ils respectent des conventions.

between the ages of 5 to 7 years old. These students attend special classes in which teachers' practices for writing instruction are similar to those of ordinary classes. This study aims to understand these students' potential to deal with written language. It also aims at contributing to reflection on ways of achieving academic and educational success. Data were collected from a five-word and one-sentence writing task administered at three different times in a school year. This task was dictated to the students and included words with different linguistic features, which provides information about various skills and knowledge students use to spell. Analyses were carried out in order to highlight these young writers' knowledge about spelling in four dimensions: visuographic, semiographic, alphabetic and orthographic[2]*. Results indicate that students' knowledge differed from one another at each assessment. Each student also showed differences in spelling skills between assessments, indicating an acquisition of new knowledge related to spelling throughout the school year, reminiscent of young neurotypical writers attending regular classes.*

La recherche est relativement rare quant aux voies à emprunter pour soutenir les premiers apprentissages de l'écrit et plus précisément, l'apprentissage de l'orthographe chez les élèves ayant des difficultés sur le plan du langage, de la communication et des interactions, caractérisant notamment le trouble du spectre de l'autisme (TSA) (Godin, Chapleau et Gagné, 2015; Saldana, Carreiras et Frith, 2009). Pourtant, les chercheurs devraient multiplier leurs efforts pour mieux appréhender le potentiel en orthographe de ces élèves pour plusieurs raisons.

D'une part, les habiletés en orthographe sont importantes non seulement pour transcrire les mots sans erreur, mais aussi parce qu'elles sont liées à celles en rédaction de texte (Graham, Berninger, Abbott, Abbott et Whitaker, 1997), en lecture (Ouzoulias, 2009) et de façon plus générale, à la réussite scolaire et professionnelle (Stanké, Dumais et Moreau, 2015). D'autre part, afin de favoriser le déploiement du mouvement mondial en faveur de l'éducation inclusive et le droit fondamental d'accès à l'éducation pour tous les enfants (Organisation des Nations Unies pour l'éducation, la science et la culture – UNESCO, 2009), il est essentiel de tenir compte de l'ensemble de besoins des élèves en matière d'accessibilité (Ainscow, 2007; Ebersold et Detraux, 2013). Certains affirment d'ailleurs qu'une combinaison riche d'approches est à privilégier plutôt qu'une réduction des connaissances mises en jeu en classe auprès de ces élèves (Unok Marks et al., 2003). Ceci renvoie à la notion d'accessibilité didactique des savoirs dans les écoles (Assude, Perez, Suau, Tambone et Vérillon, 2014), mais également aux questions d'individualisation de l'enseignement (Paré et Trepanier, 2010), centrales au développement de pratiques inclusives. Notons à ce sujet qu'au Québec, les élèves ayant un TSA sans déficience intellectuelle doivent suivre le même programme scolaire que les autres enfants, rendant essentiel le développement et le transfert de connaissances sur leur fonctionnement ainsi que sur les adaptations du programme et du matériel pédagogique (Québec. Ministère de l'éducation,du loisir et du sport, 2010) Cet article entend ainsi apporter un éclairage sur l'apprentissage de l'orthographe chez les jeunes élèves ayant un TSA et alimenter la réflexion sur les voies favorisant leur réussite scolaire et éducative.

Apprentissage de l'écriture chez les élèves ayant un TSA

Dans le cadre de cette étude, une recension des écrits a été réalisée à partir d'une recherche sur les bases de données Érudit, Repère, Psyc*INFO, Francis, Eric, Australian Education Index et CBCA Complete*, en employant les mots clés *autisme, orthographe, écriture, trouble envahissant du développement, autisme*, en anglais et en français. Entre 2000 et 2014, seules quelques études traitent de l'apprentissage de l'écrit en général auprès des élèves ayant un TSA (Asberg, Kopp, Berg-Kelly et Gillberg, 2010; Basil et Reyes, 2003; Carlson, McLaughlin, Derby et Blecher, 2009; Hellinckx, Roeyers et Van Waelvede, 2013; Kagohara, Sigafoos, Achmadi, O'Reilly et Lancioni, 2012; Schlosser et Blischak, 2004; Tanji, Takahashi et Noro, 2013), mais aucune n'a été effectuée en français. Une approche descriptive des connaissances des élèves semble également délaissée, car ces études visent plutôt l'évaluation de programmes d'intervention sur

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[2] These dimensions correspond to characteristics of words in French. Words have a visual aspect, they have a meaning, they use letters to translate sounds and they respect conventions.

des compétences diverses à écrire. Il est d'ailleurs étonnant de constater à quel point des programmes sont implantés sans se référer à des données descriptives sur le développement de l'orthographe des élèves.

Néanmoins, une autre recherche sur l'apprentissage de l'écrit (Saldana et al., 2009) réalisée auprès d'adolescents ayant un TSA et d'enfants neurotypiques, se révèle utile. Ces participants semblaient tous utiliser des stratégies similaires pour lire les mots: sémantiques, phonologiques et orthographiques. De plus, l'étude a démontré que les élèves ayant un TSA parvenaient à repérer les mots mal orthographiés. Ainsi, leurs limites sur le plan langagier ne les empêcheraient pas de présenter parfois des forces en ce qui a trait à la mémorisation d'informations et au repérage de régularités entre différents objets (Soulières, Zeffiro, Girard, et Mottron, 2011).

L'orthographe et les préoccupations du jeune scripteur

Plusieurs modèles décrivent les étapes que les scripteurs traversent lorsqu'ils développent leurs connaissances orthographiques (Bear et Templeton, 1998; Gentry, 1982; Ferreiro, 1988; Frith, 1985; Seymour, 1997). Dans le cadre de ce projet, le modèle de Montésinos-Gelet et Morin (2006) est sélectionné car au lieu de suggérer un ordre d'acquisition, il décrit diverses préoccupations possibles du jeune scripteur francophone, en fonction des connaissances et procédures qu'il manifeste en écrivant. Cet angle d'analyse pourrait dévoiler les connaissances des élèves ayant un TSA, qui peuvent présenter des habiletés orales lacunaires et des difficultés communicationnelles, et dont le développement langagier peut s'effectuer de façon atypique et tardive (Beaud, 2010; Courtois-du-Passage et Galloux, 2004).

Premièrement, selon ce modèle, le jeune scripteur peut avoir des préoccupations *visuographiques*. Il considère l'aspect visuel du message écrit en employant des pseudo-lettres, des lettres, l'orientation gauche-droite, etc. Deuxièmement, il peut avoir des préoccupations *sémiographiques* ou *lexicales* lorsqu'il réalise que l'écrit sert à véhiculer du sens. Il saisit ainsi que deux mots différents ne peuvent pas s'écrire de la même façon. De telles préoccupations se traduisent également par la mémorisation de mots fréquents, comme le prénom. Troisièmement, le jeune scripteur peut avoir des préoccupations *liées au principe alphabétique* lorsqu'il manipule et extrait les sons pour les retranscrire. A titre d'exemple, ces préoccupations se manifestent lorsque l'enfant fait preuve de conventionalité des phonogrammes (utilise des correspondances lettre-son adéquates), de séquentialité (respecte l'ordre des sons) ou d'exclusivité graphémique (n'ajoute pas de lettres inutiles). Dans une étude comprenant 575 élèves Québécois et Français, Morin et Montesinos-Gelet (2005) observent qu'en fin de maternelle, la majorité des scripteurs montre une compréhension de ce principe alphabétique. Enfin, le scripteur peut montrer des préoccupations *liées à la norme orthographique* lorsqu'il tient compte de conventions, comme la présence de lettres muettes, les marques d'accord, le choix des graphèmes (des chapeaux, plutôt que des chapo), etc.

Les pratiques d'enseignement de l'orthographe

Selon l'enquête de Daigle et Bastien (2015), les pratiques d'enseignement de l'orthographe couramment observées en classe ordinaire sont les suivantes: (a) la liste de mots que l'enseignant demande de mémoriser, (b) l'auto-enseignement, qui consiste en une exposition fréquente à l'écrit, et (c) l'enseignement qualifié d'explicite, qui comprend l'enseignement plus direct des correspondances graphèmes-phonèmes et des régularités orthographiques, les activités d'orthographes approchées, etc.

Sachant que les données sur l'apprentissage et l'enseignement de l'orthographe sont plus rares auprès des élèves ayant un TSA, cette étude vise à répondre aux objectifs suivants: (1) décrire les préoccupations de jeunes scripteurs de 5 à 7 ans ayant un TSA sans déficience intellectuelle dans une tâche d'écriture sous dictée et (2) examiner le développement de ces préoccupations à trois temps distincts dans une année scolaire.

Méthodologie

Participants

La collecte de données a été réalisée en 2014, à la suite de l'approbation du comité d'éthique de l'université d'attache des chercheuses. Quinze élèves francophones ont été recrutés, ayant de cinq à sept ans, et fréquentant trois classes spéciales composées uniquement d'élèves ayant un TSA sans déficience intellectuelle du premier cycle du primaire et ce, dans la région de Montréal. En septembre, ils sont tous capables d'écrire leur prénom, sauf une élève (C2). Les enseignantes de ces trois classes sont identifiées dans la commission scolaire comme offrant un enseignement de l'écriture conforme au curriculum. Parmi leurs pratiques, elles privilégient l'enseignement des connaissances lettre-son, les activités d'orthographes approchées et les listes de mot à étudier. Ces pratiques sont d'ailleurs répandues en classe ordinaire, comme l'indique l'enquête de Daigle et Bastien (2015). Bien qu'ils n'aient pas tous le même âge, tous les élèves de ces classes étaient invités à participer puisqu'ils suivent le même programme du 1er cycle du primaire en ce qui concerne le français. Ces élèves sont donc des scripteurs débutants, ce qui offre la possibilité d'observer leurs apprentissages tout au long d'une année.

Le tableau 1 comprend quelques données descriptives des élèves. Les élèves A sont dans la classe de Caroline, les élèves B, dans la classe de Joanie et les élèves C, dans la classe de Nora (pseudonymes). Ces trois enseignantes ont entre 10 et 17 années d'expérience en enseignement auprès des élèves ayant un TSA.

Instruments

L'épreuve d'écriture comportait cinq mots dictés (éléphant, macaroni, girafe, cerise, riz) ainsi que la phrase suivante: L'éléphant joue avec la girafe. Cette épreuve individuelle répétée (temps 1 = septembre, temps 2 = janvier, et temps 3 = avril) durait approximativement 15 minutes. Elle avait lieu dans un coin isolé de la classe, là où les élèves vont habituellement travailler lorsqu'ils veulent de la tranquillité. L'épreuve incluait enfin quelques questions ouvertes aux élèves sur leurs procédures, mais aucun élève n'a été en mesure d'y répondre. À titre d'exemple, les questions suivantes ont été posées : Comment as-tu fait pour écrire ce mot? Pourquoi as-tu choisi d'écrire ceci? Notons que dans cette étude, l'orthographe grammaticale n'était pas évaluée.

Analyse des données

Les données des élèves ont été compilées dans un tableau comprenant cinq éléments illustrant différentes préoccupations :

(a) L'exclusivité graphémique. L'élève montre qu'un mot écrit doit inclure les sons entendus, mais qu'il n'est pas nécessaire d'en ajouter. Il s'agit d'une manifestation d'une préoccupation alphabétique.

(b) Le nombre de graphèmes conventionnels et orthographiques. Dans la dictée de mots, 25 phonèmes sont à transcrire: cerise (5), girafe (5), éléphant (5), macaroni (8) et riz (2). Ce calcul permet de documenter les préoccupations alphabétiques et orthographiques, dépendamment des graphèmes choisis par l'élève. Un élève qui écrit « jirafe » montre qu'il connaît une convention : la lettre « j » peut faire le son [ʒ]. Or, la norme orthographique indique que c'est la lettre « g » qu'il faut utiliser. Ainsi, ce graphème choisi est conventionnel sans être orthographique.

(c) La présence du « e » muet en fin de mot pour les mots girafe et cerise. Ceci réfère à des préoccupations orthographiques.

(d) Le nombre de morphèmes dérivationnels utilisés. Deux mots en contiennent : éléphan**t** et ri**z**. Ceci réfère également à des préoccupations liées à la norme orthographique.

(e) La reprise de la graphie des mots dictés de façon isolée et dictés dans la phrase. Les mots girafe et éléphant, écrits de façon identique à ces deux endroits, indiquent des préoccupations sémiographiques et lexicales.

Résultats

Le tableau 2 présente les résultats des élèves aux trois temps d'épreuve. En ce qui concerne l'exclusivité graphémique, un élève qui obtient une note « A » fait preuve d'exclusivité pour tous les mots dictés. Un élève qui semble ajouter des lettres au hasard dans certains mots obtient un « B » et

Tableau 1. Présentation des 15 élèves participants

Élève	*Sexe*	*Âge*	*Capacités verbales selon leur dossier scolaire*
A1	Masculin	7 ans	• excellente communication, habiletés réceptives et expressives
A2	Féminin	7 ans	• grandes difficultés au plan du langage expressif et réceptif
A3	Masculin	5 ans	• parle peu, fait de l'écholalie différée et comprend l'oral avec du soutien visuel
A4	Masculin	6 ans	• difficultés au niveau réceptif et expressif. Montre peu d'intérêt à communiquer.
A5	Masculin	7 ans	• bonnes capacités sur le plan réceptif et expressif, mais aucun contact visuel. A besoin de support visuel.
A6	Masculin	7 ans	• bonne communication expressive et réceptive, utilise un vocabulaire riche et articulé
A7	Masculin	7 ans	• trouble du langage, grandes difficultés expressives et réceptives
B1	Masculin	7 ans	• bon langage réceptif et expressif, communique bien, mais fait de l'écholalie
B2	Masculin	7 ans	• communique bien verbalement, langage réceptif et expressif bien développés, mais s'exprime peu souvent
B3	Masculin	6 ans	• communique bien verbalement, bonnes capacités réceptives et expressives
C1	Masculin	7 ans	• bonnes capacités réceptives et expressives, communique souvent et beaucoup, se montre verbomoteur
C2	Féminin	6 ans	• trouble sévère du langage expressif et réceptif et exige des supports visuels
C3	Masculin	7 ans	• bonnes capacités sur le plan réceptif, mais certaines difficultés expressives
C4	Masculin	6 ans	• bonnes capacités réceptives, s'exprime avec des mots, des phrases et des gestes, mais peut faire de l'écholalie lorsqu'il est contrarié
C5	Masculin	7 ans	• bonnes capacités réceptives, communique bien verbalement avec des phrases courtes

celui qui en ajouterait dans tous les mots obtient un « C ». Ensuite, comme il y a 25 phonèmes présents dans les cinq mots dictés, il y a une possibilité d'obtenir 25 graphèmes conventionnels et orthographiques. Ensuite, le nombre de « e » muet peut être de 0, 1 ou 2 (ceris*e* et giraf*e*). Le nombre de morphèmes utilisés peut également être de 0, 1 ou 2 (éléphan*t* et ri*z*). Finalement, la reprise dans la phrase des deux mots déjà dictés (éléphant et girafe) peut être de 0, 1 ou 2.

Exclusivité graphémique

Les données du tableau montrent que la majorité des participants transcrit uniquement des sons présents dans les mots, pour tous les mots (A) ou pour certains mots dictés (B). Notons que certaines lettres qui semblent ajoutées ne le sont peut-être pas par hasard. Par exemple, un élève a inscrit un « p » dans le mot éléphant, mais sans le « h ». Il pourrait s'agir d'une lettre au hasard, mais on peut également penser que cet élève tente d'écrire la graphie complexe « ph ». Puisque les élèves n'ont pas pu expliquer leurs procédures, il est difficile de confirmer cette hypothèse.

Graphèmes conventionnels et orthographiques

Huit élèves sur 15 ont transcrit davantage de graphèmes conventionnels et de graphèmes orthographiques en avril qu'en septembre. À ces élèves s'ajoute B2, qui a utilisé un graphème

Tableau 2. Résultats des élèves aux trois temps d'épreuves (T1, T2, T3)

Élèves	*Exclusivité graphémique* *A = tous mots* *B = certains* *C = aucun mot*			*Nombre de Graphèmes conventionnels et (orthographiques) / 25*			*Nombre de « e » muet en fin de mot / 2 : (cerise, girafe)*			*Nombre de morphèmes utilisés (t de éléphant et z dans riz)*			*Reprise des deux mots (éléphant et girafe) dans la phrase / 2*		
Classe de Caroline (A)															
	T1	T2	T3	T1	T2	T3	T1	T2	T3	T1	T2	T3	T1	T2	T3
A1	B	B	B	12(10)	12(8)	8(5)	0	2	0	0	0	1	1	2	0
A2	B	B	A	7(7)	10(10)	6(6)	1	2	0	0	2	1	0	0	2
A3	B	B	B	23(22)	24(24)	24(24)	2	2	2	1	1	2	0	2	2
A4	B	B	B	13(12)	3(3)	22(21)	0	0	2	0	0	2	0	0	0
A5	A	A	A	23(19)	24(20)	25(21)	2	1	2	1	1	1	0	2	0
A6	B	B	B	10(9)	11(10)	15(11)	0	0	0	0	0	1	0	0	0
A7		B	A		11(10)	20(20)		1	1		1	2		1	1
Classe de Joanie (B)															
B1	B	B	B	20(17)	25(25)	23(22)	2	2	2	1	2	2	0	2	1
B2	A	A	A	25(23)	25(23)	25(24)	2	2	2	2	2	1	2	2	1
B3	B	B	B	0	3(2)	1(0)	0	0	0	0	0	0	0	2	2
Classe de Nora (C)															
C1	B	A	A	24(25)	25(23)	25(24)	2	2	2	0	1	2	2	2	2
C2	C	C	C	0	0	0	0	0	0	0	0	0	0	0	0
C3	B	B	B	7(7)	10(8)	16(14)	0	2	1	0	0	0	0	1	0
C4	A	A	A	2(1)	2(1)	2(1)	0	0	0	0	0	0	0	2	2
C5	A	A	A	22(19)	24(21)	25(22)	2	1	0	0	0	1	2	2	2

orthographique de plus en avril qu'en septembre. Ces élèves montrent donc une appropriation du code alphabétique et du système orthographique tout au long de l'année scolaire. À l'opposé, deux élèves (B3 et C2) transcrivent peu ou aucun graphème conventionnel ou orthographique. De plus, en ce qui concerne les élèves A1 et A2, leur production la plus proche de la norme orthographique n'est pas celle du T3. Pour l'élève C4, le nombre de graphèmes conventionnels ou orthographiques ne change pas d'une épreuve à l'autre.

La présence du « e » muet en fin de mot

Certains élèves inscrivent ces lettres muettes aux trois temps de l'épreuve (A3, B1, B2, C1), certains ne le font jamais (A1, A6, B3, C2), alors que d'autres ne le font qu'à un ou deux temps de l'épreuve ainsi qu'à un des deux mots seulement. De plus, certains élèves (A1, A5, C5) inscrivent ces lettres davantage en septembre ou en janvier qu'en avril.

Les morphèmes utilisés (dans riz et éléphant)

Pour ce qui est de ces morphèmes, il ne semble pas y avoir non plus de constance dans la progression chez certains élèves (A2, B1, B2). De plus, certains vont représenter un morphème sur deux en janvier et en avril, mais ce ne sera pas le même pour ces deux temps (le « t » de éléphant en janvier et le « z » de riz en avril, par exemple). C'est toutefois au temps 3 qu'un plus grand nombre d'élèves (n = 11) inscrit ces morphèmes pour l'un des mots ou encore pour les deux.

La transcription identique des mots isolés et dans la phrase (pour éléphant et girafe)

La dernière colonne du tableau indique que certains élèves représentent « girafe » et « éléphant » de façon identique dans la dictée de mots et dans la phrase lors de chaque épreuve, alors que d'autres ne le feront jamais. C'est au T2 (n = 9) qu'un plus grand nombre d'élèves utilise une graphie identique dans les deux endroits de l'épreuve. Certains élèves montrent que cette préoccupation est dominante par moments. Les élèves B3 et C4, qui n'arrivent pas à transcrire un grand nombre de phonèmes, écrivent « éléphant » et « girafe » à leur façon, mais identiquement dans les mots dictés et dans la phrase aux T2 et T3.

Discussion

Cette étude s'est intéressée à 15 élèves ayant un TSA sans DI et présentant des capacités langagières diverses, allant d'une bonne capacité à l'oral à des limites communicationnelles sévères. Les résultats ont permis d'atteindre les objectifs fixés et offrent, d'une part, un portrait des connaissances en orthographe que peuvent avoir ces jeunes élèves lors des premiers apprentissages scolaires. D'autre part, ils démontrent leur développement au cours d'une année scolaire dans un contexte d'enseignement relativement typique de l'orthographe, ou du moins, semblable à celui des classes ordinaires (voir Daigle et Bastien, 2015).

Ainsi, il est possible d'observer que ces élèves ayant un TSA démontrent des préoccupations multiples quant à l'orthographe. On remarque également qu'un grand nombre d'élèves s'améliore en cours d'année en établissant un lien plus clair entre l'oral et l'écrit. Cela vient réfuter la croyance populaire (Vacca, 2007) soutenant que ces élèves n'utiliseraient qu'une stratégie de globalisation des mots. En considérant ces nouveaux résultats, puis en tenant compte du fait que l'acquisition de l'orthographe est liée à différents processus cognitifs, à la construction du rapport à la règle, et qu'elle ne se réduit donc pas à elle-même (Manesse et Cogis, 2007), il serait donc désormais faux de croire que des élèves ayant un TSA ne peuvent s'approprier ses connaissances et ses règles.

Si des résultats semblent présenter des cas atypiques, par exemple lorsque certains élèves montrent des productions plus proches de la norme orthographique en janvier qu'en avril, il faut en juger avec prudence. Les travaux de David (2003), réalisés avec des enfants neurotypiques, montrent que ces derniers peuvent utiliser différentes logiques linguistiques lorsqu'ils écrivent et au fur et à mesure qu'ils développent des connaissances ou conjuguent des savoirs en cours d'élaboration, envisagent différentes options cognitives. Il ne s'agirait donc pas d'une perte de connaissances, mais plutôt d'une période d'ajustement occasionnée par l'articulation d'un grand nombre de connaissances.

De plus, le développement de l'orthographe entre le temps 1 et le temps 3 ne correspond pas nécessairement aux habiletés langagières des élèves, ni à leur âge. Le plus jeune participant, qui a 5 ans, ainsi que ceux qui s'exprimaient d'une façon très limitée, ont produit des mots témoignant de fortes préoccupations liées au principe alphabétique et à la norme orthographique. D'un autre côté, l'élève A6, qui avait une meilleure communication expressive, a présenté des productions de mots moins proches de la norme. Les résultats de cette étude montrent que les capacités de communication orale ne représentent pas un bon prédicteur de la réussite en orthographe chez les élèves et donc, ne peuvent à elles seules déterminer leur potentiel. Ces résultats nuancent d'ailleurs ceux démontrant un lien étroit entre leurs habiletés langagières orales et leur lecture de mots (De Weck et Marro, 2010; Godin et al., 2015). Ce lien peut sembler davantage existant auprès de C2, une élève atteinte d'un trouble du langage sévère, qui ne parvient pas à écrire son prénom et représente certains mots par des dessins en septembre. Or, les données montrent qu'en janvier, elle parvient à écrire son prénom correctement et n'utilise plus de dessins pour représenter les mots. En avril, elle utilise à ce moment 13 lettres pour écrire tous les mots. Bien qu'il n'y ait pas de correspondances observables entre les graphèmes choisis et les phonèmes dans les mots, ceci indique néanmoins des préoccupations visuographiques. De plus, en variant l'ordre de ces 13 lettres pour chacun des mots, elle manifeste des préoccupations sémiographiques et lexicales, ce qui traduit une grande amélioration dans ses apprentissages entre le début et la fin de l'année.

Enfin, puisque les élèves de cette étude présentent des préoccupations semblables à celles d'enfants en classe ordinaire, il est possible qu'un enseignement de plusieurs stratégies se référant à la complexité de l'orthographe leur soit aussi profitable. Ces résultats rappellent les approches valorisant les pratiques enseignantes inclusives envers tous (Bonvin, Ramel, Curchod-Ruedi, Albanese et Doudin, 2013) ou encore les avancées d'Unok Marks et ses collaborateurs (2003), selon lesquelles il serait plus bénéfique auprès des élèves ayant un TSA d'articuler plusieurs approches plutôt que de réduire le contenu d'enseignement.

Limites et implications de ce projet

Une première limite est liée à la répétition d'une même tâche à trois temps dans l'année scolaire. Cependant, aucune rétroaction ni aucun sur-enseignement quant aux mots utilisés dans les épreuves n'étaient offerts. De plus, très peu de données ont pu être recueillies sur les procédures des élèves car ils n'ont pas pu les exprimer. Il est alors possible que certains élèves soient parvenus à extraire correctement des phonèmes sans toutefois les transcrire de façon conventionnelle. Le potentiel de ces élèves demeure probablement à découvrir.

De plus, les analyses des données n'ont porté que sur certains aspects de chaque préoccupation. Cette étude voulait faire un premier pas vers la compréhension du potentiel des élèves et ces résultats gagneraient certainement à être bonifiés par d'autres. Ce projet suscite néanmoins une prise de conscience sur leurs préoccupations en orthographe et ouvre la porte à des perspectives nouvelles dans un domaine où la recherche est encore balbutiante.

Messages clés de cet article

Pour les personnes ayant un TSA. Des élèves ayant un TSA ont montré qu'ils peuvent apprendre à écrire les mots en français en utilisant toute sorte de stratégies. Il est primordial qu'on prenne le temps de t'enseigner ces stratégies et ces connaissances à l'école.

Professionnels. L'enseignement de l'orthographe qui s'appuie sur différentes approches et stratégies s'avère utile pour les élèves ayant un TSA. Ces élèves démontrent, tout comme les élèves de classes ordinaires, leur capacité à utiliser leurs connaissances sur la langue orale et écrite pour écrire des mots comportant différentes caractéristiques orthographiques.

Décideurs. Dans les programmes de formation et les documents officiels, il serait important d'aborder les enjeux critiques liés à l'apprentissage de l'orthographe auprès de tous les élèves en expliquant la nécessité d'employer une variété d'approches plutôt que de limiter les contenus d'apprentissage à l'égard de ceux montrant des limites sur le plan langagier ou cognitif.

Key Messages From This Article

People with ASD. Students who have an ASD can learn to write words in French using many strategies. Your teachers should take the time to teach you these strategies and knowledge at school.

Professionals. The teaching of spelling using different approaches and strategies is useful for students with ASD. These students, like students in ordinary classes, demonstrate the ability to use their knowledge of oral and written language to write words having different spelling characteristics.

Policymakers. In training programs and official documents, it would be important to address critical issues related to spelling for all students by explaining the need for a variety of approaches rather than limiting learning content for those with language or cognitive limitations.

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Supervision of Large-Scale Community-Based Early Intensive Behavioural Intervention Programs in Quebec: Description of Practices

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implementation,
supervision.

Abstract

To date, available studies have identified some components of early intensive behavioural intervention (EIBI) programs that may influence children's outcomes, including supervision. Supervisors need to be competent in several areas and must carry out various professional activities. However, it may be difficult for community-based EIBI programs to access skilled supervisors and to offer intensive supervision of staff. The purpose of this article is to present data concerning the supervision models used by readaptation centres in Quebec offering these programs. Quantitative and qualitative analyses were conducted on data collected through a survey developed as part of a larger project (2011-2012). The results from the 18 completed survey questionnaires indicated that the caseworkers most frequently asked to perform supervision were psychoeducators (38.8%, n = 7), followed by clinical activity specialists (27.7%, n = 5). At most of the centres, supervisors had a university education. Supervision frequency varied greatly, from once every six weeks to two or three times per week. When asked, "Why is there a supervision system?" respondents indicated that its purpose was to (1) ensure quality services, (2) provide training and professional support, (3) support parents and partners, (4) provide intervention support, and (5) support individuals experiencing problematic situations. Despite some differences between the data collected and the supervision modalities proposed in the scientific literature, notably in terms of supervision intensity, results emphasize the importance of supervision and the variety of possible modalities that exist (e.g., format, content). Respondents stress that supervision is a way to ensure quality services, reliable and rigorous application of the program, as well as support for professional development.

Early intensive behavioural intervention (EIBI) programs have been the subject of many scientific papers. Several studies have examined the factors that might influence its effectiveness. Thus, it is possible to identify characteristics associated with a better response to intervention, such as its duration and intensity. These results highlight the role of implementation conditions in obtaining beneficial outcomes for children (Odom, 2009).

In recent years, interest in implementation science has grown significantly (Halle, Metz, & Martinez-Beck, 2013). Among the core components for successful implementation, researchers have identified what they call "competency drivers" and "organization drivers." As explained by Metz, Halle, Bartley and Blasberg (2013), these terms have been described by Fixsen, Naoom, Blase, Friedman and Wallace (2005) as follows:

> *Competency drivers* are mechanisms to develop, improve, and sustain early childhood educators' and supervisors' ability to implement an ECE [early childhood education] program model or innovation to benefit children and families. *Organization drivers* intentionally develop the organizational supports and systems interventions needed to create a hospitable environment for a new ECE program model by ensuring that the competency drivers are accessible and effective and data are used for continuous improvement. (Metz et al., 2013, p. 28)

Among the competency drivers are personnel selection, training and coaching (or supervision). Generally, supervision may be considered a tool provided by an organization to ensure training, support and feedback related to caseworkers' performance during the implementation of a program (Chen, 2015). Supervisors play various roles within EIBI programs, notably training caseworkers, leading meetings with the caseworker team, developing intervention plans, communicating with families, and ensuring collaboration with partners (Davis, Smith, & Donahoe, 2002). Given the importance of supervisor roles, the issue of their training has caught the attention of several researchers (Davis et al., 2002; Eikeseth, 2010; Eikeseth, Hayward, Gale, Gitlesen, & Eldevik, 2009; Love, Carr, Almason, & Petursdottir, 2009).

Love et al. (2009) documented various aspects of EIBI as currently implemented, including supervision practices. Their study, conducted in the United States, shows that most supervisors have a master's degree with or without additional certification, while others have a bachelor's degree. Davis et al. (2002) also noted diversity in training among EIBI program supervisors, ranging from a doctorate combined with clinical experience, to no formal training.

Eikeseth (2010) reported that there was no clearly established training program to prepare professionals to apply, plan and supervise EIBI. However, he suggested the following minimum requirements: a postgraduate education in applied behaviour analysis (ABA), one year of supervised practical experience and having passed the Behavior Analysis Certification Board (BACB) exam. Eikeseth et al. (2009) considered that supervisors should also know the principles of learning, functional assessment and reinforcement procedures, in addition to having clinical experience.

Besides training and expertise required of supervisors, a few authors describe or propose supervision modalities in the context of EIBI programming. Eikeseth et al. (2009) specify that supervision must be performed frequently (usually once or twice per week). According to Eikeseth (2010), supervision meetings should be comprised of several activities: analyzing observation data, working with the child to adjust programming as needed, reviewing procedures for problematic behaviours, and providing feedback to caseworkers and parents. In their survey, Love et al. (2009) note that slightly more than half of supervisors report having to supervise the program of at least seven children. They almost all discuss the intervention for these children with direct caseworkers at least once a month, observe the children monthly or more frequently, and review the observation data monthly or more frequently.

Several authors feel that it is now time to focus on program structure and implementation within the community (Odom, Cox, & Brock, 2013), especially since studies pertaining to community-based EIBI programs show variability in their implementation (Gamache, Joly, & Dionne, 2011; Love et al., 2009). Despite some authors' efforts to evaluate supervision in an EIBI context (see notably the research by Eikeseth et al., 2009), the information to date is too limited and remains, in large part, theoretical. This article presents results from a larger study aimed at documenting implementation of EIBI services in Quebec, Canada (Dionne, Joly, Paquet, Rivard, & Rousseau, 2013). In Quebec, the government has opted to provide EIBI services for young children with an autism spectrum disorder (ASD) through publicly funded, community-based centres that manage and supervise personnel. These centres cover the entire population across Quebec's 17 administrative regions. Therefore, several hundred children yearly receive services from specialized public intervention centres. These services are provided by caseworkers hired by readaptation centres, which apply the program in various contexts, particularly in family home or daycare settings, but also in school and clinical environments. Most of these caseworkers have a college-level education in special education (three years post secondary school). Some also receive specialized training. A national training plan has been created in collaboration with the Quebec federation of readaptation centres for intellectual disabilities and pervasive developmental disorders, the readaptation centres, Quebec's ministry of health and social services, and three Quebec universities. This plan consists of two programs: an undergraduate certificate in intervention for persons with ASD, and a specialized graduate diploma in supervision of interventions for persons with ASD.

This article aims to document how supervision is offered to support EIBI services within large-scale community settings to provide stakeholders with information on how to improve implementation of these services. More specifically, the objectives are to: (1) document who the supervisors are in this service context; (2) determine which supervision modalities are favoured; (3) compare results to the supervision characteristics identified in the scientific literature; and (4) help, although modestly, to develop a supervision model that contributes to an implementation science framework for EIBI programs by connecting best practices and clinical field practices.

Method

This project received ethics approval from the ethical research committee of Université du Québec à Trois-Rivières, and from the *Comité éthique de la recherche conjoint destiné aux Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement* (CERC-CRDITED).

Participants

At this stage of the study, the analysis unit is an organization, more specifically a readaptation centre. All of the 22 readaptation centres in Quebec that offer services to young children with ASD were approached. Centres were recruited as part of the first stage of a larger study on the implementation and effects of EIBI programs (Dionne et al., 2013). Each centre was asked to identify the respondents most apt to provide a portrait of their program. At least two persons (three for some centres) provided data from their centres. No specific inclusion criteria were specified. Although job titles varied from one centre to another, most were research programming and planning officers, supervisors, counsellors or clinical activity specialists. All but a few had more than five years experience.

Fifteen centres agreed to participate and returned the questionnaire to the research team (68.2% response rate). The data were collected from December 2011 to July 2012. However, one centre returned two questionnaires and another one returned three because these centres covered vast territories and their practices differed by area. Therefore, 18 questionnaires, representing 18 supervision practice models, were analyzed covering most of the Quebec territory, and also the Quebec population.

Materials

A survey questionnaire, translated and adapted from Love et al. (2009) and adapted from Gamache et al. (2011) with the authors' authorization, was used in a paper-pencil or electronic format depending on respondents' preference. The questionnaire included multiple-choice, Likert-type and fill-in-the-blank questions about the participants' characteristics, the target population, intervention and service delivery protocols, implementers, organizations and community partners. The questionnaire is available upon request from the corresponding author. Once questionnaires were received, the researchers contacted the centres if any responses seemed inconsistent or incomplete. Most of the responses were clarified.

Analysis

A mixed-method (qualitative and quantitative) design was used. Descriptive analyses were performed for multiple-choice and Likert-type items. Open-ended questions were grouped and coded according to the themes that had emerged from the answers.

Results and Discussion

Who are the Supervisors in This Service Context?

When asked *"Who does the supervision?"* in their program, respondents identified a variety of caseworkers, most frequently psychoeducators (38.8%, n = 7), followed by clinical activity specialists (27.7%, n = 5). Some institutions had established precise criteria for supervisors' training or qualifications (e.g., university education, training in ABA, and at least three years' experience in supervising EIBI programs).

Program supervisors' *average education or certification level* varied. At most centres, supervisors had a university education. In fact, at three centres, 16.7% of supervisors had a bachelor's degree, at three others 16.7% had a bachelor's degree combined with a specialized graduate diploma in behavioural intervention for persons with pervasive developmental disorders (PDDs), and at two others 11.1% had a bachelor's degree with participation in the national plan for training in PDDs. Supervisors had a master's degree at six centres, including two where the diploma was combined with a Board Certified Assistant Behaviour Analyst (BCABA) or Board Certified Behaviour Analyst (BCBA) certification (11.1%), three with a specialized graduate diploma in behavioural intervention (16.7%), and one with a permit from a professional order (5.6%). At only one centre, the supervisor had a college diploma (5.6%). It should be noted, however, that three centres did not answer the question.

Which Supervision Modalities are Favoured?

As shown in Table 1, supervision *frequency* varied greatly, from once every six weeks to two or three times per week. One centre offered supervision upon request and two did not specify the frequency.

According to answers obtained in the questionnaire, supervisors *examined the observation data* on children's target behaviours weekly (5.6%), monthly (33.3%), quarterly (5.6%) or at another frequency, including twice a week (5.6%), once every two weeks (16.7%), once every three weeks (5.6%), and every three months (5.6%). At two centres (11.1%), supervisors reported that they never examined the data.

The frequency at which supervisors *observed the children* differed from one centre to another. At one centre, supervisors conducted observations daily (5.6%) and at another one, weekly (5.6%). At five centres, supervisors observed the children monthly (27.8%), at two centres quarterly (11.1%) and at another centre, yearly (5.6%). Two centres did not provide this information.

In addition to the multiple-choice questions, open-ended questions provided more in-depth descriptions of the supervision modalities. When asked *"Which content is addressed during the supervision meetings?"* respondents said that the supervisor and the supervisee discussed, notably: (1) the clinical process; (2) the intervention modalities; (3) the parents and partners; (4) the child's development, functioning and characteristics; (5) problematic situations; and (6) service organization and support offered to practitioners. The responses concerning supervision content are reported in Table 2 on page 59.

When asked, *"Why is there a supervision system?"* respondents indicated that it is a way to ensure: (1) quality services; (2) training and professional support; (3) support to parents and partners; (4) intervention support; and (5) support with problematic situations. Table 3 on page 60 shows the responses regarding supervision goals.

How do Results Fit Within the Supervision Characteristics Found in the Scientific Literature?

The first two objectives of this study were to document who the supervisors are and how supervision is offered within large-scale community service settings. Supervisors' job titles appear to reflect the Quebec reality. Psychoeducators have a master's degree and belong to a professional order. They generally intervene with individuals or groups, and act as advisors to caseworkers. "Clinical activity specialist" is a job title within Quebec's health and social services network requiring a university degree in an appropriate discipline

Table 1. Supervision Modalities

Frequency	*(n = 18)*
Monthly	(n = 5)
Weekly	(n = 5)
Variable	(n = 6)
- 3× per week	(n = 1)
- 1× every 2 weeks	(n = 1)
- 1× every 3 weeks	(n = 1)
- 1× every 6 weeks	(n = 2)
- Upon request	(n = 1)
No information	(n = 2)
Duration	*(n = 18)*
From 1–2 hours	(n = 12)
Variable	(n = 2)
No details	(n = 2)
3 hours	(n = 1)
From 1½–2½ hours	(n = 1)
Number of children	*(n = 18)*
3–4 children	(n = 3)
5–6 children	(n = 3)
>6 children	(n = 10)
No information	(n = 2)
Observation	
Data Analysis	*(n = 18)*
Weekly	(n = 1)
Monthly	(n = 6)
Quarterly	(n = 1)
Another frequency	(n = 10)
- 2× per week	(n = 1)
- 1× every 2 weeks	(n = 3)
- 1× every 3 weeks	(n = 1)
- Every 3 months	(n = 1)
Observation of Children	*(n = 18)*
Daily	(n = 1)
Weekly	(n = 1)
Monthly	(n = 5)
Quarterly	(n = 2)
Yearly	(n = 1)
Variable	
- Daily or weekly	(n = 1)
- Every 2 weeks	(n = 2)
- Every 3 weeks	(n = 1)
- Upon request or as needed	(n = 1)
- 0–3× per year, depending on the supervisor	(n = 1)
No information	(n = 2)

(Ministère de la Santé et des Services sociaux, 2015). Clinical activity specialists act mainly as resource persons for caseworkers in the field. The data concerning their training are, in part, comparable to those described by Love et al. (2009). In fact, almost all the centres' supervisors had either a bachelor's or a master's degree, with or without a specialized certification. A small percentage of supervisors had a certification in behavioural intervention.

For some respondents, there were differences between the data on which supervision modalities were favoured and those proposed in the scientific literature. In fact, the frequency of supervision was below that recommended by Eikeseth et al. (2009) at several centres, where, in some cases, it was as low as once every six weeks. Similar to the study conducted by Love et al. (2009), most supervisors followed up with six children or more. The frequency at which they examined the observation data varied considerably. As for the frequency at which supervisors observed the children, the data collected in the present study highlight major differences between the centres. The proportion of supervisors who observed children monthly or more frequently was lower than that in the study by Love et al. (2009), and one of the supervisors observed them only once a year.

The results concerning the content from this study comprise most of the themes proposed by Eikeseth (2010), including developments or changes in the child's program, intervention procedures, development/progress, observation data, problematic behaviours, and training and knowledge transfer. Other elements addressed by many respondents include relationships with partners, as proposed by Davis et al. (2002), as well as generalization and inclusion in the daycare group. Results therefore highlight the diversity and richness of the content addressed during supervision, and possibly reflects caseworkers' needs in terms of support in their practice.

For most of the centres surveyed, supervision is conducted during group meetings, possibly including the caseworkers and parents, as described in several studies (Eikeseth, Smith, Jahr, & Eldevik, 2002; Hayward, Eikeseth, Gale, & Morgan, 2009; Peters-Scheffer, Didden, Mulders, & Korzilius, 2013; Remington et

Table 2. Supervision Content

Clinical Process	*(n = 18)*
Development follow-up and review of the objectives	(n = 18)
Observation data	(n = 3)
Evaluation and results	(n = 2)
Entire clinical process in general	(n = 1)
Intervention	*(n = 18)*
Intervention techniques or strategies	(n = 12)
Generalization	(n = 2)
Approach	(n = 1)
Fidelity of the implementation	(n = 1)
Inclusion in the group	(n = 2)
Behaviour analysis	(n = 1)
Parents and Partners	*(n = 18)*
Relationships with the partners and parents	(n = 9)
Experiences in all of the child's living environments	(n = 1)
Child's functioning at home	(n = 1)
Child	*(n = 18)*
Child's development or general functioning	(n = 6)
Particularities of the child with ASD	(n = 2)
Child's health	(n = 1)
Child's characteristics	(n = 1)
Learning barriers	(n = 1)
Problematic Situations	*(n = 18)*
Problematic situations	(n = 4)
Problematic behaviours	(n = 2)
Problem solving	(n = 1)
Service Organization and Practitioners' Support	*(n = 18)*
Continuing education or knowledge transfer	(n = 2)
Record keeping and institution's standards	(n = 1)
Roles and responsibilities	(n = 1)
Caseworkers' and supervisors' mandates	(n = 1)
Number of hours of services	(n = 1)
Educator's strengths and weaknesses	(n = 1)

al., 2007). Several see it as an opportunity to observe the intervention and provide feedback. Even if some responses come close to the concept of quality, none of the centres measured implementation fidelity using a validated tool.

Despite some differences between the data collected and the supervision modalities proposed in the scientific literature, notably in terms of supervision intensity, the results show the importance of supervision and the variety of possible modalities, notably the format and content addressed. Supervision is believed to support EIBI caseworkers in their practice. Respondents stress that it is a way to ensure quality services, reliable and rigorous application of the program, as well as support for professional development. Variability in supervision practices seems to suggest a lack of uniformity across the institutions providing this type of service. That said, the purpose of this variety might be to offer several types of sup-

Table 3. Supervision Goals

Quality of Services	*(n = 16)*
Ensure the quality of the services provided	(n = 6)
Ensure reliable and rigorous application of the program	(n = 6)
Ensure standardization of the service delivery	(n = 3)
Accountability	(n = 1)
Training and Professional Support	*(n = 9)*
Training of the caseworkers and support for professional development	(n = 3)
Teaching techniques	(n = 2)
Identification of the training needs	(n = 1)
Direction with respect to the intervention approaches and strategies	(n = 1)
Help for the caseworkers in how to apply the interventions	(n = 2)
Ensuring consistency between caseworkers	(n = 2)
Parents' and Partners' Support	*(n = 4)*
Check on the parents' satisfaction	(n = 1)
Parents' level of involvement	(n = 1)
Check on the daycare centres' satisfaction with the program	(n = 1)
Respond to the questions of the people concerned	(n = 1)
Intervention Support	*(n = 14)*
Determining or revising the objectives and means	(n = 3)
Analyzing the scores and the acquisition criteria	(n = 1)
Ensuring the child's progress	(n = 3)
Having an outsider's perspective on the direct intervention	(n = 2)
Ensuring that:	
– the children's needs are met	(n = 2)
– and that the objectives established for the child are coherent	(n = 1)
Obtaining accurate observations concerning:	
– the intervention	(n = 1)
– and the generalization of the skills learned	(n = 1)
Support with Problematic Situations	*(n = 1)*
Support for the caseworkers when problematic situations arise	(n = 1)

port to caseworkers who must apply the program, enabling them to obtain different kinds of information, feedback, training or support. Therefore, more research is needed to determine which supervision modalities should be favoured for supporting the quality of EIBI practices. Moreover, the content addressed reflects the wide variety of situations and challenges that practitioners face daily (e.g., applying intervention procedures, supporting inclusion, collaborating with partners).

Need for a Supervision Model

Finally, the discussion regarding the results above is part of a reflection on the supervision model required for quality implementation of EIBI programs. Developing this kind of supervision model is one of the many challenges implementation science must attempt to address. Just like the intensity of EIBI and the nature of the interventions, clinical supervision of programs is a determining component in the attainment of objectives for children with ASD. Better knowledge of supervision characteristics will help to better define clinical practices and reduce the gap between those practices and evidence-based practice (Odom, 2009). Supervision may thus become a powerful driver behind the professional development of the caseworkers involved (Kucharczyk et al., 2012). Furthermore, it contributes to the adaptation process of evidence-based practices, making them more flexible and integrative, which is central to facilitating their social acceptability (Wood, McLeod, Klebanoff, & Brookman-Frazee, 2015).

Future Research

This study constitutes a first step towards a better understanding of the EIBI models favoured by the institutions in Quebec by focusing on the supervision modalities currently offered to caseworkers. Of course, it would be interesting to reproduce this type of study and recruit supervisors directly, to increase the number of respondents and thus produce a more detailed portrait of the situation. Despite all the excellent qualities of EIBI programs, the fact remains that specific efforts are necessary to sensitize and equip local decision makers to continue improving supervision practices, but also the entire implementation of those programs in natural settings. To do so, research teams can start by reporting the current situation, meeting with decision makers, proposing transfer strategies, and working on developing training materials in collaboration with partner centres.

Study Limitations

The results of this study, which have some limitations, must be interpreted with caution. These limitations include the limited number of centres (15 out of 22 centres); relatively mixed results; data collected from questionnaires with no direct observation of supervision; and a picture taken at a specific point in time, for only some of the institutions offering EIBI programs in Quebec. Moreover, the services offered by the centres may have changed since the time data were collected.

Despite these limitations, this study helps provide a first description of the way readaptation centres provide support through supervision in Quebec. The study also offers a few avenues of reflection for practice settings. In fact, it helps encourage institutions to pursue their efforts to support this practice within EIBI programs. Notably, it endorses the importance of focusing on supervision and its characteristics. In addition to its frequency, other aspects of supervision (meeting format, content addressed, duration) must be adjusted to help meet caseworkers' needs and promote quality interventions for children that reflect the reality of the intervention context (i.e., EIBI services in more inclusive environments). In this regard, the role and the purpose of supervision are worth establishing clearly.

Key Messages From This Article

Parents. Supervision happens in a number of different ways for EIBI interventions. There are also many ways for parents to be involved in the supervision process. It is important to be informed about how supervision occurs by service providers and to discuss the potential for involvement with the intervention team.

Professionals. Supervision has various functions and responds to various needs. It is important to be aware of supervision modalities that can promote caseworker motivation and quality of implementation.

Policymakers. Supervision is one way to ensure program quality and fidelity. Supervision modalities required for quality implementation of EIBI programs, including frequency, content, and partner involvement, must be addressed.

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Teen Dreams: Voices of Students With Intellectual Disabilities

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Abstract

High school students with intellectual disabilities who are transitioning into adult life participated in discussions of their school experiences. Utilizing deductive thematic analysis through an emancipatory critical disability lens, students responded to an individualized semi structured interview protocol aimed at engaging them in a discussion focused on their perceptions and activities as high school students and adolescents. Responses were recorded to prompts initiated by the researchers. Reporting on the lived experiences of individuals with intellectual disabilities requires researchers to acknowledge their limitations in interpreting data. As educational researchers, we strive to give voice to this often marginalized group within educational settings as well as larger society. This "giving of voice" can involve a great deal of subjective interpretation, particularly when voices of those with profound intellectual disabilities are being heard. Subverting these voices into what might be perceived as a "normalized" version to fit into the preconceived notions of researcher and reader is an inherent danger in any interpretative endeavour. In this paper, researchers made a conscious and sustained effort to listen *to the voices of teenagers with intellectual disabilities without interference. Research themes that guided the construction, collection and analysis of data were influenced by a priori knowledge and experience of the researchers as well as the existing literature.*

As perceptions of disability continue to evolve, the impetus for finding new ways to view the experiences of individuals with disabilities becomes paramount. What were historically considered fundamental tenants of disability theory have been opened up to scrutiny and debate (Meekosha & Shuttleworth, 2009; Shakespeare & Watson 2001). Much of the discourse in disability research, and the resulting development of policy for students within educational and community based organizations, has been influenced heavily by sociological and anthropological theoretical constructs of how individuals with disabilities function within the social world (Klotz, 2004; Taylor, 2000). Whether the orientation is one that characterizes the lack of fit into society being the result of deficits on the part of an individual with an intellectual disability (Edgerton, 1976) or an orientation that focuses on the relationship between social constructs and disability (Bogdan & Taylor, 1982; Laichowitz, 1988) it is clear that the threads of these orientations towards disability still exist in educational practice (Slee & Allan, 2001).

In more current literature, criticisms have arisen that research related to individuals with intellectual disability, in particular those with profound intellectual disability, lacks meaningful interpretation and participation by individuals from within that group (Snelgrove, 2005; Stalker, 1998). Barton, (2005) highlights the need for recognition and understanding, through listening, to those important and knowledgeable voices, the voices of individuals who experience disability. Efforts on behalf of experts to interpret and quantify, often through qualitative means, the experiences of individuals with intellectual disability always necessitate the adoption of a framework from which to view the individual within context. While this is a worthy endeavour, the result of applying particular orientation to that which is unknown to us can often result in misinterpretation and misrepresentation. In essence we overlap our schema onto another's reality; inevitable in research but often overdone in disability research.

The fundamental question becomes, how do we, as researchers, step far enough away to allow voice to be heard, but yet stay close enough to support and assist in the dissemination of those voices (Stone & Priestly, 1996). Within the educational context, efforts to capture the voices and experiences of students with exceptionalities have provided much needed insight into the lives of individuals with disabilities (Bentley, 2008; Snelgrove, 2005). Despite these attempts, it is clear that most of the research on students with disabilities relies heavily on reports of those surrounding the student, rather than the students themselves (Malone & Gallagher, 2010; Nowicki, 2006; Praisner, 2003). For individuals with intellectual disabilities that seems particularly true. Perhaps it is our need to interpret or to fill in what we see as blanks, to lay our schema atop what we perceive as awkward silences or lack of functional vocabulary that leads us to doubt that the student voices alone are enough. Our eagerness to assist, while in its intent altruistic, can also be interpreted as a disregard for a form of communication that is different. We often strive within education to "normalize" (Wolfensberger, 1972) students with intellectual disabilities. The quest to make them more like us is still pervasive.

Within an ever growing movement towards inclusive practices, with school boards touting their percentages of students with exceptionalities in the regular class, students' with intellectual disabilities are still segregated at staggeringly high rates; in some areas almost 50% of the student population with intellectual disabilities are still housed in self-contained classes (Bennett & Gallagher, 2012; Bentley, 2008). Within these settings, the goal is to teach life skills (often laundry and food preparation), somehow supporting the premise that experiences, within a diverse school community, navigating the lunchroom, roaming the halls, breaking into and forming cliques, are not life skills worth having and not life as a teenagers experience them.

The sociological and anthropological models that have historically driven educational practices have rooted within them a *differing* of students with intellectual disabilities. Ideological constructs of inclusion, have as a natural counterpoint othering. In essence, as noted by Baglieri, Bejoian, Broderick, Connor, & Valle (2011), the distinction between normal and abnormal remains the foundational tenant of exclusive practice. As educators we too often adopt this discourse of difference and our adherence to those models, often unquestioned after decades of use, has become a familiar habit that need to be re-examined and disregarded.

Listening is the place to start. Listening to the voices of individuals with intellectual disabilities as they experience school can provide a powerful picture of the teenager experience. The dialogue presented in this work is, to the best of our ability, unedited. It is classified into questions and responses but not interpreted, though the authors did endeavour to sort dialogue into themes. It is, we hope, a window into the thoughts, desires, and perceptions of teenagers with intellectual disabilities within inclusive high schools as they look ahead to transitioning into adult life.

Materials and Methods

Methodology

The data and findings presented in this paper are part of a larger research project which examined the stakeholder perspectives of the transitions of young adults with intellectual disabilities into the workplace. Researchers were approached by school board personnel to partner in a collaboratively developed and administered project to examine the impact of their inclusion model. This model of inclusive practice, based on a foundational tenant of the board "Each Belongs," has been in existence for a number of decades and is characterized by full inclusive practice. Quantitative and qualitative data were collected from three high schools that were recommended by the board as being exemplars of inclusion and transition. The research team was given full access to the students, staff, parents and community employers through the cooperation of the Coordinator of Student Transition. Researchers collected survey and interview data over several months during the spring term of the school year. For the purpose of this paper, the voices of the students with intellectual disabilities were used as the primary data source. Interview questions focused on factors that resulted in the bridge for these young adults into social relationships, independent work, school life and community inclusion. Survey data gathered in the larger project is reported elsewhere (see Bennett & Gallagher, 2013). Ethics review for this research study was obtained through the Brock University Ethics Review Board.

Participants

Participants within this mid-sized, urban Ontario school board included high school students (ages 16-21) with intellectual disabilities (n=21). These students ranged in terms of nature of intellectual disability (mild to profound) and some were nonverbal and nonambulatory. Some of the students with intellectual disabilities were completing their first work term as part of the school's transition program; others had several previous work placement experiences. The students with intellectual disabilities were sampled from three high schools. The schools were selected by the Superintendent and Administrator of Special Education. The students included all of those that were identified as having an intellectual disability and attended one of these three high schools.

Data Collection

Students were interviewed over a period of 3 months. Interviews were conducted with individual students by two members of the research team. One team member asked the questions while the other was assigned to keep field notes of physical gestures, facial expressions and other indicators that supported a more robust representation of the students' response. Some of the students with intellectual disabilities required assistance interpreting the questions and/or responding to the questions. The research assistants and, in some cases, the students' educational assistants, provided support for this process while efforts were made to minimize the level of interference. A majority of participants were interviewed once, with a few instances of secondary interviews for information clarification. On average interviews lasted from one to one and a half hours. The questions asked of the students focused on five areas: school life; friends; home, family & community participation; work and finally future dreams. Participants were all assigned a pseudonym to ensure anonymity. Interviews were digitally audio recorded and later transcribed. Both members of the original data collection team shared the transcription of the interviews and then shared and reviewed the materials. Changes were made based on reflection and field notes where appropriate, in particular where the recording was unclear and physical gestures of facial expressions were part of the response.

Data Analysis

Using a framework of critical disability theory (Rioux & Valentine, 2006), data analysis incorporated deductive thematic methodology to categorize stories into the pre-established themes used to generate the interview questions. Deductive themes were identified pre-transcript analysis based on the aims and objectives of the interview questions developed from the researcher's' a priori reasoning from personal experience in the field and vigorous review of the literature (Pope, Ziebland, & Mays, 2000). The five themes identified by the interview questions included school life; friends; home, family & community participation; work, and future dreams. Transcripts were examined closely, and re-read by each member of the research team in order to elicit all comments that directly related to each of these five themes. Comments were sorted manually into the corresponding themes including additional prompts and gestures that may have influenced the response in an attempt to honour the authenticity of each participant's answers. Themes were utilized in order to identify and report the patterns found in the data and for the purpose of presenting the comments of the individuals in an authentic and unaltered way (Braun & Clarke, 2006). What follows is an overall analysis of each theme with specific examples from the transcripts.

Results

Theme One: School Life

All of the 21 participants responded positively when asked about their experiences at school. They were unanimous in their communication to us that they liked school. In this inclusive setting, students were given access to the entire curriculum and decisions were made collaboratively with regard to course and activity preferences, as well as the compatibility of their preferences to their future goals. This same type of consideration and counselling, with regard to course selection would be given to any high school student. Courses that were preferred by the students were ones in which they felt actively involved such as physical education, dance, computers, music and visual arts. Only two students stated math was a favourite and three students cited English as a favourite course, noting that they enjoyed silent reading time or the discussions that they had. Three students stated gym was a class that they did not like, rationalizing it because it is tiring and they didn't like rushing to change and get to other classes. Many participants answered "yes" with no expansion or explanation, a typical response from a teenager when being asked about their school day. However some expressed reasoning behind the answer.

The following is a sampling of those student responses.

Do you like school?

Jessie: Yes and no. It matters what I said it matters what I do that day. I have stuff to do in the class that it's fun. If I don't then it's pretty boring. I like auto and construction because I'm good at hands-on and both classes involve you, like using tools and stuff in you have to do it by yourself and hands-on, so it's easier for me to understand the concept to do it.

Robert: Yes I do, I like school. I think my favourite class is art, and computers, I have no idea why.

I: Do you like gym class?

Carol: [Smiled]

Kyle: Ah yeah and no – yeah because I want to get a good future and get a good job, and do what I want to, but no because like I find there is a lot of pressure to. Do you know what I mean? I like English, and ah, well obviously phys ed. too, that's fun and it like gets my energy levels down a bit after you know what I mean? English, like I can just explain stuff, I think that's like, cause like my work ethic at school is horrible, so like when I ah… like I can explain myself out of English problems, because there's not, there's not just one answer and so I can explain my way out of it, and like phys ed. is physical, hands on, so maybe that's why I like it.

I: All right, so do you like school?

Casey: I like school, I like this school, yes (thumbs up).

I: So that's a thumbs up, all right. What is your favourite class?

Casey: Lunch, yeah

I: Lunch? Lunch is not a class.

Casey: It doesn't matter.

I: What is your favourite class?

Jason: Dance

I: Why do you like that class?

R: I love to dance.

EA: He's in the Snow White play and he's dancing, we made him "dancey," he dances all the time.

(The school's theatrical production for that year was modified specifically to include Jason.)

I: What are your favourite classes?

Peyton: Um, I like music, baking, computers, English.

I: Do you like them all?

Peyton: Yes

I: Is there one or two you like the most? What class is that?

Peyton: Music

I: Music? And why do you like that class the most?

Peyton: Because I play the maracas.

What class do you not like?

Kyle: Um, I have to say math, but I feel like I would enjoy it if I had the right teacher. Maybe

Rich: Religion, because it is boring

Sydney: Gym, because it is tiring

Sameet: Umm … Gym

I: Gym, you don't like gym class?

Sameet: No because running around does crazy things to my head.

Gavin: Mostly drama

I: Drama? Why don't you like drama?

Gavin: I hate these teachers, but Mrs. S is good, but that other one gets on my nerves.

Dale: Um, science

I: And why do you not like science?

Dale: Um, when we are doing experiments they, they explode all over me [laughing].

How does your EA/teacher help you?

Sam: By myself (indicating that he seems himself as working independently)

EA: Ok, and he helps you with your projects

Sam: And party

EA: Party? He helps you party?

Sam: Yeah (it was clear from facial expression and tone that the students was teasing). I love school.

Jessie: Ah … She helps me scribe for my tests, so like I tell her the answer and she writes it out, and she'll help me get caught up on my notes when I fall behind.

Allison: Ah … She helps me if I get stuck, yes. They help me understand what I'm doing, ah … I don't know; let's see I'm not sure.

Kyle: Um, well … the best teacher I've had was Mr. B--. Who's a religion teacher and he really cared about people really having a good future and looked at everyone the same way, type deal, like, cause some of us weren't as smart as some, he wouldn't judge them and I find a lot of my teachers, well no, just a couple, I'm not going to point them out, but like, they just bring you down, like point you down type deal, and if you are not as good as someone else, and they don't look at you the same way, and they try to make it hard on you almost I feel. And I know, it's like, oh, they are just trying to help you, but at the same time it's just kinda … I don't know …

Jessie: Because they help, they help me they help me show the technique of how to do the things, they show me how to use the tools in the class so I don't go walk over to accidentally flip the switch that blows the device up. Ah, he, if I have problems with, in the class if I don't understand how a part works he helps me explain what the part does and tells me a trick how to get the piece together.

Kyle: I think it would be like … instead of … well it depends on what teachers. Like some teachers like don't … like they give too much work, and they smother kids with work, and I'd like … some people get us and some don't. But like for someone like me, I don't have the attention span to listen to it all, but like if you gave me short lessons, I could get the work done better so I'd like them to help me, and also being a bit more understanding, but not letting me off the hook, like at the same time.

As is typical with many high schools students, when they are not engaged, they find school "boring." These students especially appreciated hands-on activities and opportunity to produce something tangible. When asked about their teachers, the attitudes of certain teachers influenced the students' judgment of a course. In particular, a teacher that respects them and doesn't judge them based on their abilities is one that is preferred. As well, a teacher who understands how they learn and is able to differentiate is highly regarded.

Theme Two: Friends

Friends were defined and referenced by the participants as those peers that are kind and help out or those peers that acknowledge the students at school. Additionally, good friends were distinguished as those peers that participants spent more time with hanging out, playing video games, attending activities together or sharing common interests.

Do you have a best friend? What makes him a good friend?

Sam: Yes, because he's sleeping over tomorrow

I: Oh, you get a sleepover tomorrow?

Sam: Yeah

EA: What makes a good friend? Why is he a good friend?

Sam: Because I love him

Dale: My friend, I actually have two of them. They both like to laugh at silly stuff. They're always there, they're always there for me, whenever I'm sad or down they're always there for me

I: So they help you out, the kids

Eli: No, (laughs)

Kyle: yes. J--.G--. he's my neighbour and we've been best friends for a couple of years.

I: Awesome. Why is he your friend?

Kyle: Well, we just I don't know. We just relate good. And we have the same interests and it's not just doing a whole lot of nothing. Kind of like we are outdoors guys, and like we never get mad at each other and when we do it's just like, it's between us and we don't make a big deal of it.

I: What makes a good friend?

Rich: When they stick up for you

I: Is that what your friend does for you?

Rich: Yes

Allison: Her name is K---. I've known her for, I've known her all my life, I've known her since kindergarten. We've had a few ups and downs but everyone does right? And um, what else? We go to each other's houses a lot, and yeah.

I: What makes her a good friend?

Allison: She's kind, she's funny, she's friendly. She listens to me sometimes [laughs]. yeah

Casey: Well, two

I: Two?

Casey: One is you

I: Oh okay! And who is the other one?

Casey: You don't know them.

I2: That's okay, we don't need to. Can you tell me about them?

Casey: He's awesome and he's a hottie.

[laughing]

I: Do you like best buddies?

Carol: Groans

I: Yeah you like it, okay.

Sameet: Um… I guess… I say L---K---

I: And why do you like her?

Sameet: Because she looks pretty.

I: Oh she's pretty? Okay.

Sameet: And she's kind to me.

I: do you have a best friend?

Jessie: um… No.

I: No?

Jessie: I don't like that stuff. I don't pick a best friend because then they backstab you and it's like oh God, so I don't pick best friends, they're all friends.

I: Well what makes a good friend?

Jessie: ah… Being honest, not being rude, that's what I got.

Students with intellectual disabilities did seem to discern between those friends that were casual and those friends that they regarded as deeply connected to. Characteristics such as being trustworthy and having integrity seemed to be foundational in the participants defining of what makes a good friend. Shared interests and spending time together were clearly important. The answers that were given by the students interviewed seem typical to what would be expected from any teen.

Theme Three: Home and Family and Community Participation

Life at home for these high school students was marked by their close relationships with their family members, particularly parents. Activities were characteristic of those that teenagers enjoy such as watching television, going movies and going out to eat. All of the participants indicated that they had some responsibilities at home and they expressed distaste for doing chores.

Do you have to do chores?

Casey: Not really.

I: No? Why not?

Casey: Don't feel like it

I: Your mom doesn't ask you to do the dishes?

Casey: That's my brother's job, not mine

I: Oh, I see, so you do nothing at home?

Casey: I'm a princess, I do nothing

Maggie: Make my own lunch

John: I have to do dishes

Taylor: I help my mom sometimes; sometimes I make my bed and help with meals and help my mom around the house with cleaning.

Drew: Yes, I clean the garage, the car wash, and the garage.

Jessie: Ah … I do recycling and garbage, I do dishes the odd time I have to help clean some of the pets.

Allison: Cleaning my room, cooking … I love to cook, except when cooking with oil.

Now, what are your favourite things to do when you are hanging out with your family, so when you are hanging out with your parents? What are the things that you like to do best?

Robert: I think it's Christmas.

I: Just Christmas? So like opening presents and having everyone together?

Robert: Yes, having everybody all together, part of my family.

Rich: Talk to them

I: What else?

Rich: Hang out with them.

I: Do you hang out what do you do when you hang out, do you play a game or you watch TV?

Rich: Watch TV

I: What do you watch?

Rich: Discovery channel

Jessie: The thing we mostly do with my family is watch a ball game or watch a movie.

I: Do you get to pick the activity that you like to do

Jessie: I have a brother so we take turns, like it will be his turn, my turn, his turn, my turn.

Gavin: Pick restaurants

I: What's your favourite restaurant?

Gavin: McDonald's

Kyle: Um with my family … with my dad, well we are sports guys, we like watching, I like the UFC like that's my thing with my dad, mom doesn't really care for it, but ah … and my mom, I've noticed, we just don't really relate a lot, like she kinda does her own thing, and she doesn't really have time much to like hang out with me and stuff … so …

Sameet: Exercise and stay healthy

Dale: Mostly watch a movie or have a friend over. We'll have a friend come over and she'll have dinner with us and then watch a movie together.

Do you do any activities, do you belong to any clubs?

Jeff: Scouts

Sydney: The band

Jessie: I play a hobby outside of school, it's called Warhammer, it's like you build small army men and you paint them and build them and play a game.

I: Do you swim?

Casey: I'm faster than you.

Kyle: I've done martial arts, for a couple of years, and, I've taken breaks off of it, but I've always had a passion, so I always go back once in a while. That's about it.

The activities that students do with their families are quite typical. Chores are manageable and well-defined (not necessarily embraced) and family leisure time is casual and enjoyable. Not all of the students with intellectual disabilities mentioned that they had community activities. For those that did mention them, all of the activities were social and involved interactions with others. Watching sports, video gaming and eating pizza, being part of a scouts group were cited as things to do outside of school hours.

Theme Four: Work

For those involved in work placements they discussed some of the responsibilities of their jobs as well as their feelings about their engagement in the work environment.

Sameet: Stack chocolate bars

I: Oh, you stack chocolate bars

Sameet: Yes

I: Oh okay. What do you do at [name of the fitness club]?

Sameet: Me? Cleaning, I find dust and office clerk

I: Office clerk, good job. And what do you do at [restaurant]?

Sameet: Me? I bus food

I: Okay. Is your job easy?

Sameet: Yes

Jessie: Ah … The job that I had was I helped, after school I helped coach basketball teams. What I liked was because I actually got the chance to help younger kids learn the basics of basketball and was able to teach them some skills

I: What did you find easy about the job?

Jessie: the explaining everything because I played basketball all the time so I already knew all the skills so it was easy to go you go this that that, it was easy to show the technique

I: what did you find hard about the job?

Jessie: Trying to get them to pay attention [laughing]. When you work with grades 4 to 6's they really don't want to pay attention [laughing].

Sydney: I do data entry and returns.

I: Where do you work?

Sydney: a video store at a health science center.

I2: Oh gosh you have three jobs? Wow

I: What do you like about your job? Do you like data entry?

Sydney: Data entry, yes.

I: Who is your employer? That would be a local store?

I2: Yes

I: Tell me about the person you work with

John: I work with … a … My job coach.

I: How do they help you? How does he help you?

John: She helping me, she's … I come in the back room, and she helps me with (figuring out where to put things) button, show what to, (unclear),

I: Could they do more to help you, or are they doing enough?

John: They help me enough.

I: Tell me about the person who helps you the most at work?

Allison: At work? Well that would have to be my supervisor, J---.

I: And what does she help you with?

Allison: She helps me if I have a hard time with the residents. She helps me because some residents, they don't talk and I don't know sign language so I don't understand what they say.

I: What do you do at your job?

Allison: I help somebody; I transport the residents to mass, on Wednesdays I help somebody with a tea, sometimes I help [unclear] with the program, yeah something like that.

I: What do you like about your job?

Allison: Oh well everybody's really, really nice. Trust me if somebody was not nice I would not want to work there.

I: Can you tell me about your job?

Taylor: well, I have two different jobs … one is on Tuesdays and Thursdays, (unclear) and one of them I put movies away,

I: Where is that, at a video store?

Taylor: Yeah, I work one day there

I: And where else do you work? You told me?

Taylor: Another night on Thursdays, I work in an office, I work at [a charity foundation].

I: Oh, very cool. What do you do there?

Taylor: I filed papers, I put them in the file and then put them away and I help out with anything else I asked them

I: Awesome, good. What do you like about your job? Or, your jobs?

Taylor: I like one of them. One of them is my favourite

I: What one do you like the best?

Taylor: The [charity foundation], they've got nice people, they know me

I: Okay

Taylor: I'd like to work there

I: Good job. And what did you find easy to do it your job?

Taylor: Well the easiest is [the charity foundation], when working with the papers and that's all they need me to do, it's not hard putting paper and files

I: And what do you find hard to do?

Taylor: Um, nothing really, there's nothing really hard there, it's so easy for me to learn

Dale: Um, well as soon as I walk into the c … As soon as I walked in I wash my hands and then I get a sticker and then I go to this, one of the classrooms that I help out with and as soon as I walk in the student's, they'll recognize me right away and they'll run up to me and give me a hug. And that is basically, I don't do anything else.

I: So do you help them with their work or … Or do you?

Dale: Yes

I: What do you like about your job?

Dale: I get to see some people from my school that go to the, from, I get his season people here that go to that, that help out at that school

I: Okay. What do you find easy to doing your job?

Dale: Helping kids with their opening up their snacks

I: What do you find hard to do at your job?

Dale: Cleaning the table, because sometimes I forget to clean off the table

I: Do you have a job coach?

Gavin: Yeah I'm get, I'm getting rid of her. I'll tell you, I don't really need her, because I can do it my own self.

I2: Very good

Gavin: I've got it all in my head

I2: Oh that's perfect, so you don't really need a job coach anymore

Gavin: No

I2: What do you do at your job?

Gavin: Um, I sit there, at noon it's [name of work] I go there twice a week, and I just do my job and then sometimes I have 2, and sometimes I go visit my grandma

I2: Oh, very nice. Now at your job what do you do?

Gavin: Help the residents

EA: Where do you work?

Drew: The office

I: In an office?

EA: Yes, at [town name], in the office

I: Oh, cool, so what do you do at work?

EA: What do you do there? Do you file, do you file the letters?

Drew: Yes

EA: Do you bring them to the people's rooms?

Drew: Yes

Experiences at work were described, for the most part, as interesting and enjoyable. Often, but not always, the participation of a job coach was considered positive. In general, these participants liked or disliked their workplace environments for the same reasons many individuals do, nice people, feeling needed and understanding the requirements.

Theme Five: Future Dreams

Dreams for the future for many of the participants included post-secondary education, gaining paid employment, having meaningful and intimate relationships and living independently. Approximately half of the participants had work experience placements. In some of these cases, they did reference these jobs as part of their future goals. Aspirations to be famous from careers in entertainment such as singing and acting were also mentioned as dreams for the future. These were supported by confident statements of their talents in these areas. Comments about marriage drew mixed reactions. Some regarded it as something not to be taken lightly while others had idealistic notions of a future partner.

What do you want to do when you leave school?

Kyle: I really want to go to university. Just like, I, I'm not the brightest kid, but that's my goal. Get into university, and have a good job. Cause don't know what I want to do but I know if I go to university it will probably help me figure out what I want to do, and it might even tell me university is not for me, so I don't know, but that's probably …

John: I would like to do … um, I to stay home, I would like to go to college.

Robert: Maybe university, I have no idea, I think I'll stay home. My sister comes back on holidays

Drew: I'm going to buy a motorcycle

EA: You just want to drive your motorcycle?

Drew: Yeah, you can ride too, an extra helmet, you can put it on.

Where do you want to work?

Jason: Future shop

Dale: Well when my mom was little she always wanted to be, she's really good at singing and movies so I want to follow in her footsteps. I would like to focus on singing.

Jessie: Um … Become an auto mechanic.

Maggie: I haven't thought about it.

Casey: I'll be on TV and [in] Hollywood.

Robert: Hmmm … I could be a weatherman

I: A weather man! Cool! That's a lot of schooling though, are you ready for that?

Robert: Yeah

I: Yeah well I think you can do it.

Robert: Yes I will

Do you want to live on your own?

I: Do you want to live on your own

Maggie: (Smiling)

Drew: Yes

Robert: Yes

How about get married?

Jessie: I don't know about that one, it's not, haven't thought about that yet. I'll worry about that when the time comes

Maggie: I'm too young.

Sydney: A couple of years later

Peyton: Haven't really thought about it?

Sameet: Nope, I'm too young.

As with many students in their high school years the participants in this research were unsure of their plans for the future. Some had plans that were based on current experiences and others had dreams of a far distant future. Captured in the interviews were aspirational statements based on hope and cumulative life experiences. Given the inclusive nature of their school experiences it is not unrealistic to suppose that these types of discussions are part of a more general one participated in by most students within this age range.

Discussion

While in general the characterization of students with special needs has seen improvement in terms of facilitating and supporting groups with disabilities to speak out, conduct research as partners and inform policy with regard to their disability, in the area of individuals with intellectual disabilities much work still needs to be done. Calls for inclusion resound within school systems across the world but still, as overall statistics for inclusive education increase, students with intellectual disabilities are not considered equal. In the province of Ontario, while more than 79% of students with special needs are included in the regular classroom (2012/2013) (Bennett, Dworet & Weber 2013) for all of part of the day, 80% of students with intellectual disabilities are still in self-contained classroom settings all or part of the day. This statistic has not changed over the past number of years.

What is it about this population of students that seemingly makes it so difficult to include them into regular schooling? Some would purport that students with intellectual disabilities need to be protected and provided with specialized programming in small class size settings (Zarghami & Schnellert 2004). Others would discuss the difficulty that students with intellectual disabilities have interacting with regular class peers or the larger school environment (Thompson, Whitney, & Smith 1994). We would contend that the most persistent and pernicious barrier to successful inclusion for students with intellectual disabilities is attitude. (Abbott & McConkey, 2006; de Boer, Pijl, & Minnaert 2011) Not the attitude of students with intellectual disabilities but the attitudes of those who feel entitled to make decisions for them. As noted by Taylor (2000) the acknowledgment of disability is not a declaration of master status. Indeed identity of an individual is, for all of us an interaction between how we perceive the world and indeed how the world perceives us. Similar to Goffman's (1959) premise we are actors and it is our audience that often forces us into our roles as they define them, students with intellectual disabilities are at time a victim of perception.

This work provides a glimpse of students with intellectual disabilities in a completely inclusive high school setting. These students are teenagers, who like many teenagers are struggling for what Erikson (1968) would describe as self-identity. Establishing who they are in relation to their changing role and status; being able to develop by participating in new experiences; and forming different relationships that lead to adulthood are all essential component of adolescent development. (Kupersmidt & Dodge, 2004; Santrock, J., Woloshyn, V., Gallagher, T., Di Petta, T., & Marini, Z. (2010).). The teenagers in this study were provided with an opportunity to talk about how they perceive school, home, friends, employment and their future. Their audience is one that has for decades has adhered to a philosophy that all students are full and included members of the school community. For some participants, those interactions were rich with verbal discussions, while other participants were more comfortable with a yes or no. Students who were nonverbal represented a small group but participated willingly in the discussions. A nod, a smile and any type of vocalization was considered their response; as valid and as meaningful as those who responded in more familiar ways. We have attempted to use their words as authentically as possible. What their words show are reflective of their experiences, best friends, caring teachers, loving families and legitimate hopes for success and love in their adult life; not inherently different from what we would perceive to be any teenagers' hopes and aspirations. Students with intellectual disabilities are not different from their peers, we just make them so.

Key Messages From This Article

People with disabilities. Your voice is important, especially when it comes to your own future. You have important things to say about your experiences and about what you want to do with your life as you transition from high school. Speak up and make sure your desires and dreams are heard by those around you who can help you to accomplish your goals.

Professionals. The experiences and opinions of young people with intellectual disabilities are fundamental when ensuring their successful transition from secondary school. Consider their ideas, goals and dreams and recognize them as valid and important in preparing students for workplace entry or post-secondary studies.

Policymakers. Policies for the transition of students with intellectual disabilities from high school must include student voice. With necessary supports, they are able to clearly articulate their experiences and future goals. In order for transitions to be successful, policies must reflect the voices of the students themselves.

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Are Rural and Urban Ontario Health Care Professionals Aware of Fetal Alcohol Spectrum Disorder? A Secondary Data Analysis of the Fetal Alcohol Syndrome Survey for Health Professionals

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Abstract

Health care professionals play a critical role in the prevention of FASD, particularly through providing counselling around alcohol use and alcohol consumption during pregnancy, yet researchers have demonstrated that many professionals remain under-educated concerning FASD. In addition, awareness of FASD held by Ontario health care professionals remains unexplored. A secondary data analysis was conducted using data obtained from the 2001-2002 Fetal Alcohol Syndrome (FAS) Survey for Health Professionals. Ontario-specific data (N = 834) were used to examine the awareness of FASD held by various health care professionals in both rural and urban settings. Nearly all (99.5%) of the surveyed health care professionals had previously heard of FASD; however, only 73.2% reported discussing the risks of alcohol during pregnancy, 62.4% agreed with the practice of telling patients to drink in moderation, and only 87.9% recommended that pregnant women completely abstain from alcohol for the duration of their pregnancy. Using Chi-squared comparisons, results also showed that rural providers were more likely than urban providers to ask pregnant women if they are currently drinking alcohol (p = .007) and felt more prepared to care for biological mothers in the area of alcohol use or dependency (p = .011). Health care professionals' counselling and recommendations for pregnant women about alcohol use, as well as FASD prevention, are discussed.

Fetal alcohol spectrum disorder (FASD) is an umbrella term that refers to a continuum of effects associated with prenatal exposure to alcohol. Prior to the introduction of new Canadian guidelines for the diagnosis of FASD (Cook et al., 2015), the term was used to describe a range of conditions on the spectrum including fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), partial FAS (p-FAS), and alcohol related neurodevelopmental disorder (ARND; Streissguth et al., 2004). These terms are now antiquated given the new updated guidelines; however, the terms FAS and FAE are used throughout this paper as this was the terminology employed in the original questionnaire, prior to the development of clear diagnostic guidelines.

Estimates for the prevalence of FASDs are relatively undetermined due to challenges with the diagnostic process. A number of "diagnostic dilemmas" influence reported FASD prevalence rates, including challenges with changing diagnostic criteria and changing facial characteristics (e.g., less pronounced facial characteristics over time), inconsistencies in the level of understanding of the disability, as well as the perceived stigmatization of the label of FASD for both families and children (Chandrasena, Mukherjee, & Turk, 2009). However, researchers who have estimated the prevalence of FASD have reported an approximate rate of 1 to 6 per 1,000 live births in the general population (Stade, Stevens, Ungar, Beyene, & Koren, 2006), with some estimates as high as 9.1 per 1,000 live births in both Canada and the United States (Alberta Alcohol and Drug Abuse Commission, 2004; Chudley et al., 2005). A recent study examining the prevalence and characteristics of FASD among first grade students in a representative Midwestern United States community found that as many as 1 in 20 children may have an FASD, indicating that FASDs may be much more prevalent than previously predicted (May et al., 2014).

Researchers have demonstrated that parents frequently perceive health care professionals and service providers to be unaware of the signs and symptoms associated with FASD (Brown & Bednar, 2004; Caley, Winkelman, & Mariano, 2009; Salmon, 2008) and consequently parents often feel unsupported by medical and health care professionals (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Ryan, Bonnett, & Gass, 2006; Salmon, 2008; Sanders & Buck, 2010; Watson, Hayes, Coons, & Radford-Paz, 2013). Current research involving families of children with FASD in Ontario reveals that while a minority of families reported that accessing formal support from professionals such as psychiatrists, paediatricians, and family physicians, was helpful, the majority of families felt that doctors lacked knowledge of FASD and were therefore not effective (Coons, Watson, Schinke, & Yantzi, 2016). Despite a relatively large body of literature examining knowledge, attitudes, and awareness of FASD in Canada in general, the United States, and Australia, limited research has examined the level of awareness of FASD held by Ontario health care professionals.

Lack of Knowledge, Awareness, and Understanding of FASD

Health care professionals play a critical role in the prevention of FASD, particularly through guidance regarding alcohol consumption during pregnancy. National survey results suggest that Canadian health care providers require further training and education regarding both individuals at risk for having a child with FASD and for individuals with FASD, as well as their families (Clarke, Tough, Hicks, & Clarren, 2005; Tough, Clarke, Hicks, & Clarren, 2005a, 2005b). In particular, findings indicate that health care professionals need assistance in making valid diagnoses and referrals (Clarke et al., 2005; Public Health Agency of Canada [PHAC], 2005a). Only 60% of health care providers surveyed in two studies accurately recognized the most correct information concerning a diagnosis of Fetal Alcohol Syndrome (FAS) according to the diagnostic systems in place at the time (e.g., a combination of growth, brain, and facial abnormalities; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Clarke et al., 2005).

In addition to Canadian findings, international studies in the United States and Australia have identified similar deficits in health care professionals' knowledge of FASD (e.g., Anderson et al., 2010; Elliott, Payne, Morris, Haan, & Bower, 2008; Payne et al., 2005; Payne et al., 2011a; Payne et al., 2011b; Payne et al., 2014). For example, a study of 1143 Western Australian health professionals identified that only 67% of general practitioners routinely ask about alcohol use during pregnancy, with 24% indicating that they "sometimes" ask (Payne et al., 2005). Payne et al. (2011b) conducted a follow up study of paediatricians in Western Australia and found that only 27.1% of their sample routinely asked about alcohol use when taking a pregnancy history and few physicians (10.1%) routinely provided information to their patients about the consequences of alcohol use during pregnancy. Few general practitioners said they routinely gave information regarding the consequences of alcohol on the fetus and 17% said they did not provide this information at all to their patients (Payne et al., 2005).

Elliott et al. (2008) also found that 23.3% of paediatricians in Australia did not routinely ask about alcohol use when taking a pregnancy history. Unfortunately, Payne et al.'s (2011b) study also found that few paediatricians reported feeling very prepared to deal with FAS (e.g., ~6%) and more than two thirds (67.1%) believed that giving a formal diagnosis of FAS was stigmatizing to the individual with FASD and their family. Findings from Anderson et al. (2010) also demonstrate breakdowns in the continuity of care for individuals with FASD. Specifically, less than half of obstetricians and gynaecologists in their United States study responded that they always communicate information about alcohol use during pregnancy to the newborn's paediatrician.

Compared to all other professional groups, midwives demonstrate significantly better knowledge of FASD and pregnancy counselling. For example, in a Western Australian study, Payne et al. (2014) found that 93.2% of midwives asked pregnant women about their alcohol consumption and 99.4% provided pregnant women with advice about alcohol consumption during pregnancy (e.g., not drinking in pregnancy is the safest option). However, almost half of midwives thought that asking every pregnant woman about their alcohol consumption during pregnancy could distress or anger their patient, could cause anxiety and guilt, could lead to feelings of judgment, and could uncover complex problems that are difficult for midwives to address. Additionally, 32.1% of midwives believed that infrequent consumption of a standard drink of alcohol during pregnancy is not harmful to the fetus or the mother (Payne et al., 2014). Similar results have also been demonstrated with other professional populations, such as family physicians, general practitioners, and obstetricians or gynaecologists, who indicate that one or more drinks per week or per occasion are likely safe for a pregnant woman (e.g., Anderson et al., 2010). These findings indicate that while different provider groups all have some level of knowledge regarding FASD, misconceptions and stereotypes also exist.

Rural and urban differences may also be relevant because suggested prevalence rates of FAS have been found to be highest in rural and remote communities (Tough, Ediger, Hicks, & Clarke, 2008; Viljoen, Croxford, Gossage, Kodituwakku, & May, 2002). Tough and colleagues (2008) examined differences between rural and urban health care providers in Canada with regards to their knowledge of, attitudes about, and awareness of FASD and preconception counselling practices. Despite few differences between rural and urban care providers' general knowledge and diagnostic knowledge of FASD, rural providers were in fact more prepared to access resources for women with addiction issues and were more likely to care for patients with an FASD (Tough et al., 2008). Tough et al. (2008) also found that rural providers were significantly more likely to report caring for patients with FAS and to have referred a patient for diagnosis. Despite this demonstrated knowledge of FASD among rural and remote communities across Canada, the level of knowledge of FASD within Ontario remains unclear.

Because families of children with FASD in Ontario frequently report feeling under-supported by those from whom they expect help (Coons et al., 2016), it is essential to understand what these various professionals know about FASD. While researchers have addressed the level of knowledge of FASD held by health care professionals in Australia, the United States, and Canada as a whole, to the authors' knowledge, no study has examined the level of knowledge held by Ontario health care providers. It is especially relevant to focus on under-researched populations, such as midwives, and those from regions of extremely underestimated numbers of FASDs, such as Northern Ontario.

A secondary analysis of the Ontario-specific data collected as part of the 2001–2002 Fetal Alcohol Syndrome (FAS) Survey for Health Professionals will provide insight into the awareness and comprehension of FASD held by Ontario health care professionals in the early 2000s. Though the data are 15 years old, creating limitations in the understanding of health care professionals' current level of knowledge and awareness concerning FASD, the analysis of this information is timely and relevant as it provides an insight into the historical attitudes and knowledge of health care providers prior to established diagnostic guidelines. By examining historical knowledge, we are better able to understand whether or not updated guidelines and training conducted over the past decade have been effective in increasing awareness of FASD, and in understanding the context of service delivery in Ontario. This analysis will assist in determining the previous level of knowledge surrounding FASD, as well as health care providers' common practices and recommendations, held prior to the release of national guidelines addressing FASD, which were first established in 2005 (Chudley et al., 2005) and recently updated in 2015 (Cook et al., 2015). By better understanding how, and to what extent, knowledge has evolved over time, the creation of new policies regarding best practices, as well as education and training plans, will be better informed.

Methods

The Fetal Alcohol Syndrome (FAS) Survey for Health Professionals (Clarke et al., 2005; PHAC, 2005a; Tough, Clarke, Hicks, & Clarren, 2004; Tough, Clarke, Hicks, & Clarren, 2005a, 2005b) is a questionnaire designed for Canadian health care professionals, including paediatricians, psychiatrists, midwives, family physicians, and obstetricians/gynaecologists. The questionnaire consists of four parts: general knowledge; prevention issues; diagnostic issues; and background information. The primary study was undertaken to obtain national information from physicians and midwives across Canada regarding their levels of knowledge, attitudes, and beliefs about FAS and related conditions. The questionnaire was available in English and French, and participants had the option to complete the survey as either a web-based version or in a paper format.

Data for the original national study were collected between March 2001 and October 2002. A random representative sample of 5,361 health care professionals were selected from membership lists, including the Canadian Paediatric Society, the National Association of Midwives, the College of Family Physicians of Canada, and the Society for Obstetricians and Gynaecologists of Canada. The overall participation rate for the national study was 41.3% (PHAC, 2005a), resulting in a sample size of 2,216 health care professionals. For the purposes of this study, only the Ontario specific data are examined. Ethics approval was sought from the principal investigators of the original study and permission was given to access the de-identified, Ontario specific data from the national study. In addition, ethical approval for this study was obtained from the Laurentian University Ethics Board, Ontario, Canada, and is in line with the Canadian Tri-Council Recommendations for Research with Human Participants.

A total of 884 participants from Ontario completed the FAS Survey for Health Professionals. After screening the data, health care professionals who did not indicate their medical specialty or specify whether they considered their practice to be urban or rural were removed from the analyses. Participants who included multiple answers, entering that they perceived their practice to be both rural and urban, were also removed from the analyses. In total, fifty participants were removed, leaving a final sample of 834 participants. Information outlining participant areas of specialty and demographics can be found in Table 1.

Table 1. Participant Demographic Characteristics

Demographic Characteristics		
Health care provider (*n*)	834	
Paediatrician *(%)*	276	*(33.1)*
Psychiatrist *(%)*	168	*(20.1)*
Midwife *(%)*	56	*(6.7)*
Family Physician *(%)*	278	*(33.3)*
Obstetrician/Gynaecologist *(%)*	56	*(6.7)*
Average age (*SD*)	46.2	*(10.6)*
Urban (*Rural*) (%)	84.2	*(15.8)*
Southern (*Northern*[a]) (%)	94.0	*(6.0)*
Male (*Female*) (%)	52.0	*(48.0)*
English (*French*) (%)	99.4	*(0.6)*
Percentage of Practice[b] (%)		
Aboriginal	6.0	
Women (16+)	43.9	
Children (≤15)	43.8	

Note: a = provider practicing in Northern Ontario defined as any region north of Parry Sound
b = Percentage does not equal 100, as providers could indicate that their practice covers more than one area

Data were analyzed using Statistical Package for the Social Sciences (SPSS)/PC Version 20.0. Descriptive analyses and chi-square tests were performed to better understand this sample of health care professionals, as well as their knowledge, attitudes, and practices related to FASD. Data were pooled for analyses and individual responses were not identifiable. Participant responses to open-ended questions were also examined and analyzed using a thematic analysis approach (Braun & Clarke, 2006) to identify patterns and themes from participant comments.

Results

The results presented in this paper focus on the province of Ontario, given the recent emphasis from families of children with FASD who report being unsatisfied with health care providers' knowledge of FASD (Coons, Watson, Schinke, & Yantzi, 2016; Coons, Watson, Yantzi, & Schinke, 2016). Results for the national sample have been presented elsewhere (see PHAC, 2005a).

Health Care Provider Knowledge and Awareness

When asked whether they had previously heard of FAS, nearly all (99.5%) of survey respondents replied "yes." In addition, the vast majority of professionals (98.4%) reported first learning about FAS more than four years ago. When considering their own personal practice within the past five years, professionals were asked if, in their practice, they had ever diagnosed a patient as having FAS, cared for a patient with FAS, suspected, but did not diagnose, a patient as having FAS, or referred a patient to confirm a diagnosis of FAS. About 40.4% of individuals indicated that they had cared for patients affected by FAS and 30.2% confirmed that they had personally diagnosed patients with FAS in their professional practice.

Participants were also asked about their perceptions of barriers to the diagnosis of FAS (see Table 2). Over a quarter of professionals indicated that diagnosing FAS was outside of their role. Interestingly, while the majority of professionals indicated that diagnosing FAS was within their scope of practice, 16% of paediatricians (compared to 15.1% of paediatricians nationally; PHAC, 2005a) and 24.5% of family physicians (compared to 23% of family physicians nationally; PHAC, 2005a) indicated that making a diagnosis of FAS was beyond their professional responsibilities, two populations that would likely be involved in the decision to diagnose a child with FAS. It is possible that family physicians may initially suspect an FASD, but may make a referral to a specialist to confirm the diagnosis, particularly in certain cases. Obstetricians and gynaecologists did not indicate that diagnosing FAS was outside of their role as practitioners, but disagreed that any of the listed factors were barriers to diagnosing. Not surprisingly, most midwives (64.3%) indicated that diagnosing FAS was separate from their range of care, given that the focus of their work does not include long term follow up with the mother or the child.

Table 2. Barriers to Diagnosis of FAS by Professional Group

	Is making a diagnosis of FAS beyond the scope of your practice?		*Lack of time needed to make a diagnosis*		*Lack of specific training to make a diagnosis*		*Belief that making the diagnosis will not make a difference to the individual*		*Other reasons*	
	Yes (%)	*No (%)*	*Yes (%)*	*No (%)*	*Yes (%)*	*No (%)*	*Yes (%)*	*No (%)*	*Yes (%)*	*No (%)*
Paediatrician	16.3	83.7	20.9	79.1	67.6	32.4	13.4	86.6	11.6	88.4
Psychiatrist	39.9	60.1	9.9	90.1	47.9	52.1	13.6	86.4	8.0	92.0
Midwife	64.3	35.7	3.9	96.1	23.5	76.5	3.9	96.1	2.0	98.0
Family Physician	24.5	75.5	24.2	75.8	70.4	29.6	11.9	88.1	4.0	96.0
Ob/Gyn	0.0	100.0	0.0	100.0	0.0	100.0	0.0	100.0	0.0	100.0
All Groups	27.7	72.3	17.3	82.7	57.2	42.8	11.4	88.6	6.9	93.1

Nearly three-quarters of family physicians (70.4%) agreed that a lack of specific training was a barrier to the diagnosis of FAS, compared to 23.5% of midwives. However, only 11.4% of interviewed professionals believed that making the diagnosis would not make a difference for the individual with FASD. Several health care professionals listed other reasons that may impede the diagnosis of FAS including: social stigma; the diagnosis is difficult and unreliable; the facial characteristics and physical features can be ambiguous; a lack of truthful or accurate history of maternal drinking; a fear of over-diagnosing a condition; full syndrome FAS compared to FAE is not common in community practice; do not see patients with FAS/FAE or do not see enough patients with FAS/FAE; and parental resistance, denial, and anger to receiving the diagnosis. Some professionals also noted their own lack of experience and lack of knowledge of FASD.

When professionals were asked from what sources they have gained knowledge about FAS and FAE, 63.8% of health care providers reported obtaining knowledge of FASD from either medical school, a residency, or a fellowship; however, this proportion dropped to 51.8% and 25% respectively for psychiatrists and midwives. Other sources from which professionals obtained their knowledge of FASD included medical journals and books (78.9%), mass media (44.2%), colleagues (41.0%), and parents/patients (19.8%). However, when considering rural health care providers specifically, a greater proportion of these individuals gained information from more informal sources, such as mass media (53.0%), colleagues (50.0%), and parents/patients (27.3%).

What Advice Do Providers Give?

Approximately 3 out of 4 (73.2%) surveyed health care providers responded that they discuss the risks of alcohol consumption during pregnancy with female patients of childbearing age. Only 5% of health care providers believed that discussing alcohol use during pregnancy will frighten or anger patients. In addition, although 93.7% of those surveyed agreed that they asked all pregnant women in their care whether they were currently drinking alcohol, only 87.9% of respondents recommended complete abstinence from alcohol during pregnancy, indicating that 12.1% of respondents still condoned or recommended some level of alcohol consumption during pregnancy. Furthermore, while 87.9% of respondents agreed with the statement that "no alcohol is recommended," differences in the interpretation of the question potentially leave room for other recommendations or suggestions to patients (e.g., no alcohol is recommended, but occasional consumption may not pose any risks). Also troubling is the finding that not all participants agreed (92.2%) that prenatal alcohol exposure poses a significant risk for permanent brain damage.

Nearly 1 in 10 health care professionals provided counsel other than abstaining from alcohol during pregnancy, including "a glass of beer or wine in moderation was okay" (8.8% of respondents), or offered no specific suggestions in regards to prenatal alcohol consumption. Furthermore, only 80.5% of participants acknowledged that they discuss what their patients think "in moderation" means (e.g., a range of 3 to 13 drinks per week). While many participants condoned moderate alcohol consumption, they struggled to provide a consistent definition of what "moderation" meant.

"I do not use the term 'in moderation'": Defining Moderate Alcohol Consumption

Of the professionals who completed the survey, only 62.4% agreed with the practice of telling patients (both male and female) to drink in "moderation." However, little consistency existed around the definition of "moderation." One-way ANOVAs were performed in order to determine differences between health care professionals' specialties and their definition of "moderate alcohol consumption" in terms of both the reported number of drinks per occasion and the reported number of drinking occasions per week for non-pregnant women. No significant differences were found between professional specialties in terms of drinks per occasion (although significance was approached – $p = .062$); however, family physicians ($M = 3.44$, $SD = 2.32$) reported a significantly higher number of drinking occasions per week as "moderate alcohol consumption" when compared to paediatricians ($M = 2.31$, $SD = 1.90$) and midwives ($M = 2.51$, $SD = 2.36$) ($F_{(4, 787)} = 9.42$, $p < .001$, see Figure 1). Bonferroni post-hocs revealed that no other differences existed between professional specialties.

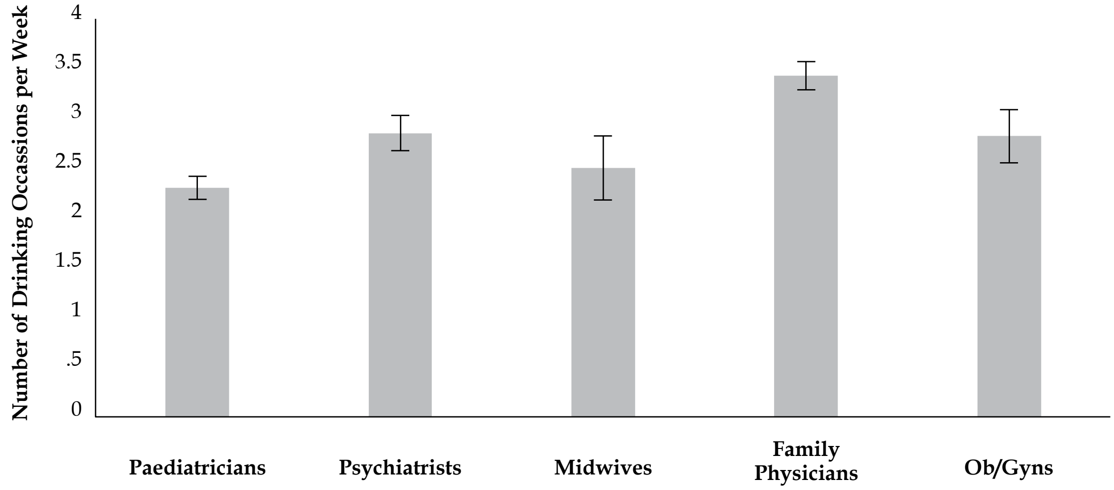

Figure 1. Mean difference values representing differences between providers regarding the number of drinks per occasion that are considered to be associated with a moderate level of alcohol consumption. Standard errors are represented in the figure by the error bars attached to each column

Participant responses to open-ended questions also indicated confusion over a definition of "moderate" alcohol consumption. Some participants indicated that "we do not know what a moderate level is" and that they were "uncertain if any level is 'safe' at any time of pregnancy." However, other participants indicated that "*occasional* alcohol use" or alcohol consumption "1–2 times per week" was a moderate level of consumption. In addition to discrepancies in professionals' definitions of moderate alcohol consumption for non-pregnant women, professionals reported many exceptions and situation-specific recommendations concerning best practices and guidelines for pregnant women regarding alcohol use during pregnancy.

"One or three, depends on the patient": Inconsistent Recommendations

Participants were provided with five choices and asked which statement best describes the advice they give pregnant women regarding alcohol use during pregnancy. 12.2% of health care professionals indicated providing a recommendation other than abstinence from alcohol consumption during pregnancy. Health care professionals specified many instances that they perceived to be acceptable (or unacceptable), including existing stereotypes of FASD (e.g., FAS only occurs in patients who have alcohol use problems), occasional drinking across different trimesters, differing amounts of alcohol consumption (e.g., low dose exposure), and drinking on special occasions.

"If no history of alcohol abuse, I say OK in moderation": FASD stereotypes. Several participants prescribed to the stereotypical belief that FAS and FASD are particularly problematic only for women with alcohol use issues. One participant noted that "an occasional glass of wine or beer is okay. Unless [the] person is truly an alcoholic, then I recommend none," demonstrating that some professionals may condone occasional drinking during pregnancy for women who they perceive to not be alcoholics. In the open-ended responses, participants also discussed that binge drinking was particularly dangerous, especially for women who were high risk.

"Occasional drink is fine only after first trimester": Perceived differences across trimesters and timing of exposure. While some health care professionals acknowledged that binge drinking is "never okay" and is "dangerous" at all times during pregnancy, when asked to provide open-ended responses, numerous professionals reported that occasional or moderate drinking was "fine only after [the] first trimester." One professional noted that their definition of moderation was "abstinence in [the] first trimester." Several professionals echoed these remarks, stating that alcohol should be avoided during the first trimester, but that "occasional use throughout (i.e., one drink per occasion) will not harm mom or baby" and that "once passed first trimester, patient can have occasional drink, one drink per week or so." One family physician indicated that "up to one to two drinks, one to two times a week throughout all trimesters is OK."

Some professionals also identified challenges regarding addressing alcohol consumption before pregnancy identification. One physician noted that they "try to assure women who report occasional alcohol use in first weeks of pregnancy before knowing about pregnancy" in an effort to prevent feelings of panic or guilt. However, several professionals believed that "limited or moderate exposure before pregnancy diagnosed [is] not supported as high risk" and "a few drinks before know[ing] about pregnancy is okay."

"But no harm shown for occasional consumption": Amount of alcohol consumption. Closely tied to the discrepancy regarding the timing of exposure is the debate regarding the acceptable amount of alcohol exposure during pregnancy. Many physicians who did condone alcohol consumption during pregnancy indicated that drinking should be "occasional," "rare," and should only include "very limited alcohol," "one drink," or a "half glass." However, no statements included a definition of what "one drink" entailed and no professionals identified that "one drink" should be a standard drink. Professionals also provided varying responses regarding the amount of alcohol that should be consumed during a week or during the duration of pregnancy. For example, professionals' diverse responses included "two drinks per week," "one to two glasses of wine during pregnancy," "maximum one drink per week," "half glass maximum per week," "half only per day," and "one drink, three to four times per week."

"Occasional drink for special occasion only": Perceived exceptions. When asked which recommendation best describes the advice that professionals give to pregnant women regarding alcohol use during pregnancy, the most common "other" response that professionals gave was that alcohol consumption was acceptable for special occasions only. Birthdays, anniversaries, and Christmas were some of the notable special occasions included. Again, responses varied regarding how much should be consumed on these special occasions. Responses included: "one glass of beer or wine for special occasion and not more than one drink per week," "occasional drink," "a sip of wine or beer," "one half glass of champagne or wine for a celebration, not more than once a week," and "one glass on wedding anniversary." While some professionals did indicate that "there is no safe quantity of alcohol determined for pregnant women," and in order to "err on the side of caution, no alcohol should be consumed," these responses were rather limited in the open-ended responses (n = 12).

Health Care Provider Differences

Chi-squared analyses were performed to determine whether health care providers felt that managing problems in the area of alcohol use was either the responsibility of the physician or the midwife (see Figure 2). Physicians and midwives were asked to what degree (e.g., strongly agree, agree, disagree, strongly disagree) they perceived it to be the physician's role or the midwife's role to manage problems in the area of alcohol use. Significant differences existed between the responses of health care providers when asked whether it was the responsibility of the physician to manage patients' problems in the area of alcohol use [χ^2 (8, n = 826) = 19.28, p = .013]. Most family physicians (88.1%) agreed with the statement, whereas only 69.2% of midwives agreed with this statement. Also of note was that 5.3% of respondents were undecided as to whether it was the responsibility of the physician or not.

When considering whether midwives were responsible for managing problems in the area of alcohol use, significant differences were also found [χ^2 (8, n = 822) = 16.63, p = .034]. Interestingly, a large number of physicians (72.5%) also agreed that it was the midwives' responsibility, and once again, fewer midwives endorsed the same statement (56.6%). In this case, 9.0% of those who completed the survey were unsure as to whether or not it was the responsibility of the midwife to deal with patients' alcohol use problems.

Figure 2. Percentage of providers who agree that it is the role of a physician or a midwife to manage problems in the area of alcohol use

Rural and Urban Provider Differences

Location of practice, whether in a rural or urban setting, and its influence on whether professionals asked all pregnant patients about their drinking habits (i.e., if currently drinking alcohol) was determined using chi-squared analyses. The results indicated that a significantly greater proportion of rural health care providers (99.1%) asked their pregnant patients about their alcohol use when compared to urban providers (91.6%) [χ^2 (1, n = 382) = 7.34, p = .007].

Chi-squared analyses were also performed to determine differences between rural and urban health care providers in terms of diagnosing FAS in patients as well as caring for patients affected by FAS as part of their practice. Results suggested that the proportion of rural and urban professionals who reported diagnosing FAS in patients was not significantly different. In contrast, a significantly greater proportion of rural providers (49.6%) reported caring for patients affected by FAS in their practice compared to their urban counterparts (38.8%) [χ^2 (1, n = 769) = 4.78, p = .029].

Additional analyses indicated that more rural professionals (61.9%) felt prepared to care for birth mothers in the area of alcohol use or dependency than those practicing in urban settings (48.7%) [χ^2 (1, n = 620) = 6.47, p = .011] (See Figure 3). Individuals within the following

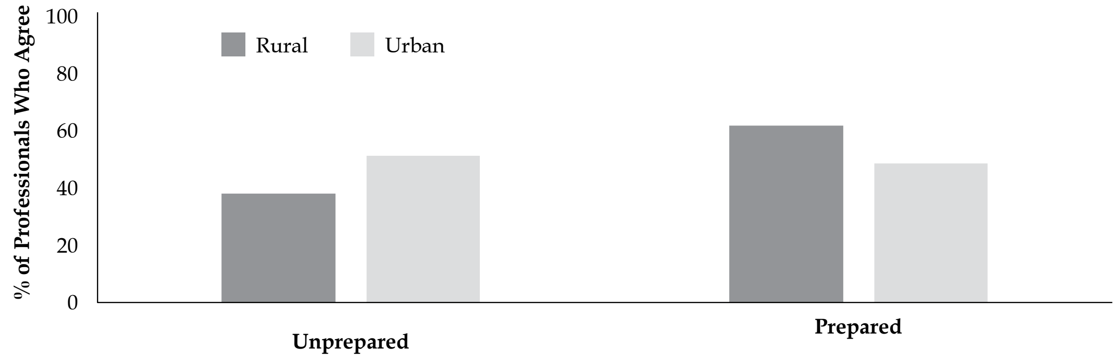

Figure 3. Percentage of rural and urban providers who feel prepared or unprepared to care for biological mothers in the area of alcohol abuse or dependency. Rural providers are more likely to report feeling prepared when it comes to caring for biological mothers in the area of alcohol abuse or dependency (p = .011)

professional groups in rural settings, including obstetricians/gynaecologists (83.3%) and family physicians (65.3%), indicated feeling more prepared to care for birth mothers, compared to psychiatrists (42.9%), paediatricians (42.9%), and midwives (30.8%). However, no significant differences were found between rural and urban health care providers' preparedness to care for pregnant women (rural: 58.4%, urban: 49.6%) or individuals affected by FAS in the area of alcohol use or dependency (rural: 50.4%, urban: 47.1%).

Discussion

The authors of this secondary data analysis found that, in general, health care professionals in Ontario were aware of FASD. However, some professionals did not believe that alcohol exposure during pregnancy is a significant risk for brain damage and did not agree that abstinence from alcohol during pregnancy is the best recommendation for women. The authors also found that some confusion existed regarding scope of practice in addressing and diagnosing FASD. For example, one quarter of participants indicated that diagnosing FAS was beyond their professions' responsibility and over half of participants indicated that lack of specific training was a critical barrier to diagnosis and knowledge of FAS and FASD. Participants also identified various sources from which they obtained their information regarding FAS and FAE, including from the mass media and from parents and individuals with FASD, which have implications for the quality and accuracy of information that they receive about FASD.

The finding that not all health care providers recommended complete abstinence during pregnancy is the most disconcerting result from this secondary data analysis. While 87.9% of surveyed Ontario health care professionals agreed with the statement that no alcohol is recommended during pregnancy, compared to 87.5% of professionals who responded to the national survey (PHAC, 2005a), more than 1 in 10 providers did not agree with this statement and cited exceptions to this recommendation (e.g., occasional or light drinking is likely not dangerous, drinking during pregnancy is only problematic for women with alcohol use problems). Also of concern is that several providers who did agree with the recommendation that no alcohol is recommended gave open-ended responses indicating that there are sometimes exceptions or circumstances where occasional or moderate drinking is acceptable (e.g., drinking on special occasions). These findings suggest that professionals may not be providing consistent and clear recommendations to all pregnant women or women of childbearing age.

Women of childbearing age, whether planning on becoming pregnant or not, should be informed of the risks of alcohol consumption during pregnancy. However, challenges exist if health care providers are unaware of, or do not apply, recommended clinical practice guidelines. For example, the Public Health Agency of Canada (2005b) recommends a better implementation strategy of the existing clinical practice guidelines advocating that no alcohol be consumed during pregnancy. These suggestions mirror the recommendations of the Canadian Centre on Substance Abuse (Finnegan, 2013) for *Canada's Low Risk Drinking Guidelines*. Unfortunately, inconsistent public health policy and varying standards can create confusion as to which recommendations professionals should follow. It is also important to note that these data were collected before these strategies were established.

In 2010, the Journal of Obstetrics and Gynaecology of Canada, in conjunction with the Canadian Association of Midwives, the Association of Obstetricians, the College of Family Physicians of Canada, and the Society of Rural Physicians of Canada, published the *Alcohol Use and Pregnancy Consensus Guidelines* (The Society of Obstetricians and Gynaecologists of Canada [SOGC], 2010). The SOGC refer to themselves as the 'official voice of reproductive health care in Canada' (SOGC, 2010). In the clinical guidelines, the SOGC determined that there is evidence that alcohol consumption during pregnancy can cause fetal harm. However, the SOGC concluded that there is insufficient evidence regarding fetal safety or harm at low levels of alcohol consumption during pregnancy (SOGC, 2010). In rat models, Goodlett, Marcussen, and West (1990) demonstrated that a single exposure to alcohol in late pregnancy could cause a severe loss of brain cells. More recently, findings from a longitudinal study of 607 individuals prenatally exposed to alcohol demonstrated that alcohol exposure at each trimester predicted increased behaviour problems. The authors conclude "there is no safe level or safe time during pregnancy for women to drink" (Day, Helsel, Sonon, & Goldschmidt, 2013, p. 1). While the SOGC does recommend that abstinence is the cautious choice for a woman who is or might become pregnant, considerable debate still exists regarding low levels of alcohol consumption during pregnancy. Inconsistent messaging can lead to confusion between research evidence and suggested practices, and may partly explain the participants' mixed responses in this study.

Despite an identified need to address alcohol consumption during pregnancy and FASD, Canadian findings suggest that less than half of family physicians discussed the risks of alcohol use, drug use, or smoking during pregnancy with women of childbearing age (PHAC, 2005a; Tough et al., 2005a). Only 73.2% of health care professionals in this study reported that they discussed the risks of alcohol consumption during pregnancy with female patients of childbearing age; however, this proportion is nearly twice the national frequency of 40.1% (PHAC, 2005a). These findings suggest that improvements in information exchange between health care professionals and patients on key health issues may be warranted, in particular clarifying the definition of moderate alcohol consumption and the repercussions of alcohol and drug use during the prenatal period and/or pregnancy. Less than half of health care professionals in Canada reported frequently discussing these issues with women of childbearing age (Tough et al., 2005a).

Providing clear and consistent information to women is also critical (Raymond, Beer, Glazebrook, & Sayal, 2009), as a "faulty information delivery system" (Anderson, Hure, Kay-Lambkin, & Loxton, 2014, p. 5) between the provider and the patient can lead to varying perceptions and interpretations about 'safe levels' of alcohol consumption during pregnancy. Anderson et al. (2014) found that when women received various and conflicting information regarding alcohol use during pregnancy, they created a hierarchy of information, often relying on health care providers to explain these discrepancies. Women not only view their health care provider as a reliable source of information, but also believe they hold *expert* knowledge (Anderson et al., 2014). Therefore, if health care professionals are ill-informed about the risks of prenatal alcohol exposure or do not provide their patients with valid information (e.g., if they condone moderate or light drinking or indicate that alcohol is only dangerous during the first trimester), professionals are potentially increasing their patients' risks of having a child with a FASD.

It is also important to understand where professionals are obtaining their information regarding FASD. Almost half (44.2%) of health care professionals in general, and over half (53%) of rural professionals specifically, in this study identified that they received their information about FASD from the mass media. Trusting potentially unreliable sources can be problematic, given the recent social movement towards encouraging mild to moderate alcohol use during pregnancy. For example, economist Emily Oster's book, "*Expecting Better: Why Conventional Pregnancy Wisdom Is Wrong – and What you Really Need to Know,*" created considerable controversy in 2013 when she concluded that current research shows that it is harmless to drink a limited amount of alcohol during pregnancy. Michelle Ruiz also generated debate with her Cosmopolitan article in October of 2014 entitled "*Why I Drank While I Was Pregnant.*" Both media sources cite highly criticized research and conclude that light to moderate drinking during pregnancy poses no risk to the fetus.

This movement is concerning, given research trends that demonstrate that health care professionals are increasingly accessing their information about FASD from mass media sources, as also demonstrated by the results of this study. For example, Payne et al. (2011a) noted that obstetricians and gynaecologists, in particular, cite the media as one of their main sources of information. Additional research has also shown that an increasing proportion of paediatricians report being informed about alcohol use during pregnancy by the media (Payne et al., 2011b). While the majority of health care professionals continue to gain knowledge about FAS and FASD from journals and books (Payne et al., 2011a), fewer professionals, compared to an earlier study of the same population, reported gaining their knowledge of FASD from scientific, peer-reviewed journals and books (Payne et al., 2011b). These findings indicate a need to disseminate accurate information, in a useful format, through the media.

Importantly, some health care professionals in this study also indicated accessing information regarding FASD from parents and patients with FASD, but the percentages of professionals who did so were rather low, with only 19.8% of professionals in general and 27.3% of professionals practicing in rural communities indicating that they obtained information in this way (compared to 24.1% of respondents in the national survey results; PHAC, 2005a). These percentages may speak to the challenges reported by families of children with FASD who express their frustrations at not being heard by their child's health care provider and frequently cite these professionals as being unsupportive (Coons et al., 2016; Watson et al., 2013).

Health care professionals in this study also identified that there was confusion and overlap surrounding whose role it is to manage FASD. Because FASD crosses many sectors of society (e.g., health, education, social services), and individuals with FASD and their families access many different health care providers, these varying perspectives may be, in part, related to challenges determining whose scope of practice it is to primarily address FASD. These varying perspectives are also likely due to the fact that, depending on the patient's circumstances (e.g., pre-partum or postpartum), diverse providers may play the primary role. For example, midwives and obstetricians or gynaecologists play an important role in the primary prevention of FASD and are responsible for a woman's health during pregnancy and immediately afterwards. Different timings of responsibility may account for the finding that a smaller proportion of midwives agreed that it was their responsibility (56.6%) than those who agreed it was the physician's responsibility (69.2%). However, a large proportion of midwives still agreed that it was their role, indicating that some professionals may feel that it is not the sole responsibility of any individual health care provider to manage FASD. The importance of role clarity is crucial as a clear understanding surrounding one another's roles and responsibilities promotes successful interprofessional collaborations between physicians and midwives (Munro, Kornelsen, & Grzybowski, 2013). Contrastingly, Munro and colleagues (2013) found that a lack of understanding between physicians and midwifes regarding each other's scope of practice could lead to challenges in providing interdisciplinary care to pregnant women, especially in rural communities.

Furthermore, paediatricians and family physicians may also play a more central position in directly managing the individual with FASD, as opposed to a woman of childbearing age or a pregnant woman. Research has demonstrated that paediatricians are often called on to provide a medical home for children with FASD, and therefore are responsible for coordinating mental health services, providing consultations to special education programs, and managing medications for attention deficit hyperactivity disorder or other comorbid mental health disorders (Gahagan et al., 2006).

Findings from this study also demonstrated some variability in health care professionals' experiences in diagnosing FAS. Many professionals indicated that diagnosing FAS was beyond their scope of practice, and cited a number of barriers that can impede their ability to diagnose FAS. Research findings from Gahagan et al. (2006) showed that paediatricians may specifically express a reluctance to concentrate their efforts on diagnosing FASD, as they perceive it to be an untreatable condition. Future medical education should include known benefits of early diagnosis and intervention for children with FAS and FASD, such as the potential for preventing secondary disabilities.

Finally, findings from this study also indicated that rural health care professionals asked more of their pregnant patients about their alcohol use, cared for more patients with FAS in their practice, and felt more prepared in particular situations (e.g., to care for birth mothers), compared to their urban counterparts. The scarcity of paediatric specialists in rural areas could lead to other health care providers treating patients with FASD in their daily practice. In other practice settings, such as larger urban centres, professionals may be more likely to refer their patients to see a specialist (e.g., geneticist, developmental-behavioural paediatrician, or neurologist) for additional evaluation or assessment if necessary (Gahagan et al., 2006). Rural professionals may also have more training and more experience in the area of FASD, as they are expected to have more generalized practices and generally see more patients. This preparedness is likely due to rural providers having more exposure to individuals with FASD (attributable to the higher prevalence rates in rural areas), as well as rural providers seeing more patients with FASD than their urban counterparts (Tough et al., 2008).

Limitations and Future Directions

Although this study was the first study to address the level of knowledge of FASD held by rural and urban Ontario health care professionals, a number of limitations presented, predominantly the age of the data used for the secondary data analysis. These data are 15 years old, and as such may not reflect the current level of knowledge held by practicing health care professionals today. This study should be updated, utilizing the original data as a baseline for comparisons, and additional research should be conducted to determine the level of knowledge of FASD held by health care professionals in Ontario today. Additional research should also examine the level of knowledge of FASD held by future health care professionals to determine if students are adequately educated about FASD during their medical training. Future research should also address health care students' and health care professionals' feelings of self-efficacy in working with women of childbearing age, pregnant women, and individuals with FASD.

Because of the age of the original data collected, there are also differences in the terminology used (e.g., FAS, FAE). The term FASD is now used as a diagnostic label, with the differentiation of FASD with and without sentinel facial features (Cook et al., 2015). The new diagnostic guidelines also include an at risk category for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure (Cook et al., 2015). Health care professionals today may have a different level of knowledge of FASD, given the changing terminology of the disabilities included under the spectrum. However, research has shown that health care professionals do tend to have better knowledge of FAS compared to other disabilities on the fetal alcohol spectrum, which may be influenced by a focus on FAS specifically in medical education or the overshadowing of FASD as a topic in medical education (Nanson, Bolaria, Snyder, Morse, & Weiner, 1995). Additionally, because of the changing terminology, some of the issues identified in this study (e.g., changing diagnostic criteria) have likely been lessened since the time the original study was published. The role of professional counselling in primary prevention of FASD should continue to be stressed in medical education curricula, so that future generations of providers will incorporate these principles into their practice (Zoorob, Aliyu, & Hayes, 2010).

In addition to the age of the data, the original study did not include an operational definition of rural. Health care professionals were asked to indicate whether or not they perceived their practice to be rural or urban. This self-perception created some confusion, as a number of providers indicated their practice was both rural and urban. In line with recent rural health research, future research with this population should include an operational definition of rural, as different definitions generate a different number of rural people or professionals. Despite its limitations, this study used a large sample size and a very thorough survey to demonstrate the level of knowledge held by health care professionals in Ontario.

Conclusion

FASD is a preventable disability and health care professionals play a key role in its prevention; however, results from this secondary data analysis indicate that many physicians, midwives, and other health care professionals may have inconsistent knowledge regarding the impact of prenatal alcohol exposure. Consequently, women of childbearing age may be receiving mixed messages from health care professionals, resulting in confusion and potentially harmful behaviours. Clear, consistent recommendations regarding alcohol use during pregnancy are required in order to prevent FASD and its potentially devastating effects. By understanding the knowledge deficits of health care professionals, these gaps can be targeted and subsequently addressed in health care education and training.

Key Messages From This Article

People with disabilities. You should have access to educated health care professionals who are aware and understand your disability. You should also feel confident and comfortable with the level of care provided by the doctors that you see.

Professionals. FASD is a preventable disability that you have a critical role in preventing. Professionals need to be educated about FASD and provide accurate advice to pregnant women. Professionals need to be wary of the information they obtain from the mass media; information regarding FASD should be obtained from more scientific sources.

Policymakers. FASD is a preventable disability. Ontario needs a provincial strategy to address and prevent FASD. This strategy should include educating health care professionals about FASD as a major priority.

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Journal on Developmental Disabilities
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Announcements

Thank You to Volunteers Involved With the Journal on Developmental Disabilities

The *Journal on Developmental Disabilities* (JoDD) would not exist without involvement of committed and dedicated volunteers who are involved with its production. In particular we thank and honour: Dr. Ann Fudge Schormans and Dr. Lynn Martin who have stepped down after years of expert involvement on the Chief Editorial Board, and Dr. Jonathan Weiss who will soon be stepping down from this role; Dr. Carly McMorris and Dr. Melody Ashworth for their valuable input as JoDD Associate Editors and Connor McGuire as JoDD Assistant Editor; and to Dr. Jay Rao who is stepping down as Chair of the Ontario Association on Developmental Disabilities Publication Committee. Very special thanks are in order for the many individuals who served as reviewers of manuscripts submitted during the 2016 calendar year (see list below).

Welcome on Board

JoDD welcomes: Dr. Carly McMorris, Department of Psychology, University of Calgary, to the JoDD Chief Editorial Board; Jo-Anne Link, Executive Director of Brantwood Community Services, as OADD Publications Committee Chair. Volunteers who join the JoDD production team will be acknowledged in future issues of JoDD.

JoDD Reviewers of Manuscripts Submitted During 2016

Charles Anyinam
Wendy Barber
Priscilla Burnham Riosa
Christina Carnahan
Regina Carroll
Stacy Clifford-Simplican
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Susan Farrell
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Peter Sturmey
Shrinidhi Subramaniam
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Shelley Watson
Jonathan Weiss
Larry Williams

Keywords

Ontario Association on Developmental Disabilities (OADD),
Journal on Developmental Disabilities (JoDD),
JoDD reviewers,
JoDD Student Publication Prize

Winner of the Brown & Percy *Journal on Developmental Disabilities* Student Publication Prize

About the Student Publication Prize

The Brown and Percy *Journal on Developmental Disabilities* Student Publication Prize … is intended to … "encourage student contribution to the journal." The prize is awarded to an author of what is judged to be the most outstanding student contribution published in a particular calendar year. A student contribution is deemed to be a paper that has been successfully peer-reviewed and published in the *Journal on Developmental Disabilities* based on research or ideas of someone who is currently a student, or of someone reporting work completed while he or she was a student (e.g., a thesis).

Normally, an eligible author for this award would be the first author of the paper though exceptions are made. The prize carries a cash value of $500 in Canadian funds, and is awarded with a plaque and letter of notification about the honour. When two individuals tie for first place, the cash award is split and two plaques are awarded. In the case of a runner-up, the recipient receives a letter of notification about the honour. Funds for this award come from profits generated by the OADD textbook *Developmental Disabilities in Ontario* and are donated by the book editors.

Kyle Pushkarenko was awarded first place in the competition for papers published during 2016. Particulars of the winning paper are: "Pushkarenko, K., Gregory Reid, B., & Smith, V. (2016). Effects of enhanced structure in an aquatics environment for three boys with autism spectrum disorders: A pilot study. *Journal on Developmental Disabilities, 22*(2), 3–15". The prize was presented via Skype on April 21, 2017, at the Annual Research Special Interest Group Symposium held at the Hilton/Fallsview Hotel, Niagara Falls, ON.

ABSTRACTS FROM THE 2015 RSIG RESEARCH DAY THOROLD ON, APRIL 17 – PRESENTATIONS

Dimensions of Treatment Quality and Their Relation to Child Characteristics and Outcomes

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Objectives

Intensive Behavioural Intervention (IBI) is the treatment of choice for young children with autism spectrum disorders, however outcomes are variable. This variability may be due to child, family, and treatment factors. Research has focused on treatment quantity with little attention given to quality, in part because it is difficult to measure. The York Measure of Quality of IBI (YMQI; Perry, Flanagan, & Prichard, 2008) is the only systematic measure used to define and evaluate the quality of IBI, based on video segments of children engaged in IBI. A recent study showed good psychometrics of the measure overall, however indicated that the YMQI may be measuring different dimensions of quality (Blacklock, Shine, & Perry, 2013). Our most recent poster (Blacklock, Taheri, & Perry, 2014) presented an exploratory factor analysis of the YMQI which revealed four factors: Pace and Organization; Engagement and Motivation; Technical Correctness; and Generalization. Next, we will explore how these different aspects of IBI quality change over approximately one year in treatment, as well as how they relate to child characteristics at the start of IBI and after one year of intervention.

Methods

As part of a larger IBI study (Perry, Dunn Geier, & Freeman, in preparation), 402 monthly videos of 38 children were coded using the YMQI. Subscale scores based on the above-mentioned factors will be calculated. We will graphically examine how these subscale scores change over one year. We will also examine the relationship between initial child characteristics (age, autism severity, cognitive and adaptive level) and treatment quality subscale scores. Next, we will explore the relations of the subscale scores to children's outcomes (cognitive and adaptive skills, and autism severity at outcome, as well as cognitive and adaptive rates of development during IBI). Finally, regression models with interaction terms will be estimated in order to examine how the interactions of the YMQI subscale scores with child characteristics at the start of IBI are related to children's outcomes.

Results

By examining the subscale scores of the YMQI across time, we will explore which aspects of IBI quality show drift, improvement, or stability over one year. By examining the relationship of the subscale scores to child characteristics at the start of intervention, we will explore whether children with different characteristics receive treatment that is focused more on specific aspects of quality. Finally, we will explore whether these relationships, and whether intervention focused on specific aspects of quality, leads to different outcomes.

Discussion/Conclusions

The quality of IBI is very rarely examined, and has not been looked at across time in a treatment program. This research will be the first to do so and to examine the relationship between aspects of IBI quality to child characteristics at the beginning of IBI as well as their outcomes after approximately one year of intervention. This research will have implications for IBI training and supervision and will inform future research on the quality of IBI.

Getting Enough Supplements? A Preliminary Study on Treatment Response in 22Q11.2ds-Related Hypocalcemia

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Objectives

Hypocalcemia is highly prevalent in 22q11.2 deletion syndrome (22q11.2DS), the second most common genetic cause of developmental delay after Down syndrome. Hypocalcemia in 22q11.2DS is generally the result of inadequate parathyroid hormone secretion, but low levels of magnesium and/or hypothyroidism may also be relevant. The presentation of hypocalcemia varies from symptomless to life-threatening situations such as serious cardiac arrhythmias and tonic clonic seizures. Common symptoms include fatigue, emotional irritability, tingling, carpopedal spasm and abnormal involuntary movements. Hypocalcemia is treatable with vitamin D, calcium, with/without magnesium supplementation. However, to the best of our knowledge, treatment response in 22q11.2DS has not been studied.

Methods

We reviewed medical records of 72 adults with a confirmed 22q11.2 deletion and a history of hypocalcemia. We selected 22 patients (15 female, 7 male; mean ± SD 31.0 ± 8.8 year); full scale IQ (FSIQ) mean ± SD 69.4 ± 10.5) with documentation in our records of at least 1 calcium assessment < 1.12 mmol/L ever. Subsequently, we checked "last visit" laboratory pH-corrected ionized calcium (calcium) levels as an indicator of treatment response. We correlated calcium levels with FSIQ, and with "last visit" intact parathyroid hormone (PTH), thyroid stimulating hormone (TSH) and magnesium levels. Patients were excluded from the study when laboratory results were > 5 years ago. We used parametric tests. All analyses were two-tailed and performed using SPSS; p values < 0.05 were considered significant.

Results

All 22 patients were recommended to take supplements; vitamin D (n = 22), calcium (n = 21) and magnesium (n = 6). 14 out of 22 adults with previous calcium levels < 1.12 mmol/L also demonstrated "last visit" calcium levels < 1.12 mmol/L (mean ± SD 1.10 ± 0.07). No significant correlations were found between calcium levels and FSIQ, levels of PTH, TSH, or magnesium.

Discussion/Conclusions

These preliminary data suggest that many adults with 22q11.2DS and hypocalcemia are not achieving normalization of calcium levels. Future research, including assessments of compliance with treatment and dosages of supplements, is necessary in formulating recommendations and long-term care plans for patients with 22q11.2DS.

A Family-Researcher Partnership: Behind the Scenes of the "F-words" in Childhood Disability Integrated Knowledge Translation Journey

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Objectives

In 2012, Drs. Rosenbaum & Gorter published: "The F-words" in childhood disability: I swear this is how we should think!" Transforming the World Health Organization's (WHO) ICF Framework into a fun and memorable framework, the article highlighted six factors important to ALL children's development – Function, Family, Fitness, Fun, Friends, and Future. Unbeknownst to the authors at the time of publication, the "F-words" would soon begin to capture the attention of families, practitioners, and researchers around the world. The objective of this poster is to take you behind the scenes of the "F-words in Childhood Disability" Knowledge Translation (KT) journey thus far and to explore how an integrated team of families and researchers are working together to move the "F-words" concepts into practice.

Methods

Since the "F-words" paper first appeared, it has been downloaded > 790 times and presented at > 30 local, national, and international meetings. Although these diffusion strategies are useful for targeting the scientific community, additional KT strategies are needed to capture the attention of a broader audience. In early 2014, we formed an integrated "F-words in Childhood Disability" research team with the goal to spread awareness of the "F-words" ideas to potential knowledge users – especially families and practitioners. Our first project included the development, implementation, dissemination, and evaluation of a family-centred "F-words" awareness video. The project followed a formalized multi-staged KT process and was carried out over a five-month time period. The video, posted on the CanChild website, used written descriptions, parents' reflections, pictures, music, and graphics to captivate the audience. Various dissemination/publicity strategies (i.e., emails, social networks, etc.) were utilized to distribute the video. The video was evaluated over a two-month period by tracking the number of views and through an online survey. Subsequently, the team has presented at five conferences and the video has been entered into the CIHR IHDCYH Talks Video Competition.

Results

After the initial two-month evaluation, there were 715 views and 137 survey responses. Of the survey responses, 89% lived in Canada, 55% had not previously heard of the "F-words," 98% "extremely liked"/"liked the ideas," and 88% indicated they would share the video. The video is still posted on the CanChild website (www.canchild.ca) and currently has > 990 views on YouTube. In the CIHR IHDCYH Talks Video Competition the video received a total of 1,697 views and 290 likes in one month.

Discussion/Conclusions

Creating an online video was only the first step in moving the "F-words" into practice. As a feasible and low cost project, the video allowed us to spread awareness to a wide audience, inspire new ideas, and gather insight into the reception of the "F-words" concepts, before undergoing a larger KT initiative. Engaging families throughout the project was critical to the success of our work. Families are the experts in their children's lives and we encourage practitioners and researchers to work with families as equal partners.

Health Profile of Transition Age Youth With Developmental Disabilities

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Objectives

Individuals with developmental disabilities (DD) often have complex health needs, and experience difficulty in accessing appropriate services. While there is a growing literature on these issues with respect to adults with DD, few studies have focused on transition age youth (TAY), who are moving from the child to the adult system. The current study examines the demographics and incidence of health conditions of TAY with DD compared to a random sample of TAY without DD.

Methods

Health Care Access Research in Developmental Disabilities (HCARDD) is an ongoing collaborative program developed to address disparities in health status and health care access faced by individuals with DD in Ontario, Canada. The current study analyzed data from a sample of 15,980 Ontarians with DD ages 18–24 years. The sample was derived from a larger cohort of 66,484 individuals with DD ages 18–64 as of April 1, 2009, constructed by linking Ontario administrative health data held at the Institute for Clinical Evaluative Sciences and social services data held by the Ontario Ministry of Community and Social Services. The comparison sample is a 20% random sample of Ontarians without DD ages 18–24 years (N = 393,263). Descriptive statistics was used to compare the demographics between the two groups. Logistic regression was used to compare the groups on incidence of mental health or addictions diagnoses. Groups were also compared on a measure of overall morbidity (Resource Utilization Band) that sorts people into five categories ranging from "healthy" to having "high morbidity."

Results

As a group TAY with DD were more likely to be younger, male, and live in poorer neighbourhoods and less likely to live in urban areas compared to TAY without DD. Over forty-four percent (44.5%) of TAY with DD compared to 21.1% without DD had a psychiatric or substance abuse diagnosis ($OR = 2.97$, $p < 0.001$). On the measure of overall morbidity TAY will DD were more like to fall into the moderate, high and very high morbidity categories and less likely to fall into the healthy and low morbidity categories compared to those without DD, $d = 0.43$.

Discussion/Conclusions

Transition age youth with DD have greater health and mental health needs compared to their same age peers. These differences are important to understanding their health care access needs.

Interprofessional Education and Practice in Developmental Disabilities and ASD: From Classroom to Community at Queen's University

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Background

With the deinstitutionalization movement in Canada, health care professionals are caring for a greater number of individuals with intellectual disabilities (ID) in their practices, and inevitably require additional training to provide this care. At Queen's University, the Division of Developmental Disabilities, has responded to this need, developing innovative educational curriculum promoting interprofessional education (IPE) and collaborative practice (IPC) as it relates to ID curriculum and health care provision. A developmental curriculum was provided across three teaching initiatives to graduate health care students by facilitating an introduction, exposure, experience and advanced practice in ID and ASD. Evaluation was collected across all three courses and research conducted on the introduction to ID course.

Objectives

The overarching curriculum purpose was threefold (1) to foster IPE learning across and within disciplines; (2) develop awareness and benefits of IP collaborative client-centred practice; and (3) to provide consumer exposure and engagement with individuals with ID and ASD. The purpose of this study was to measure health care students' change in knowledge, skills and attitudes towards individuals with ID and how it affects their readiness for interprofessional care. The research was targeted at graduate students from the fields of medicine, nursing, clinical psychology and rehabilitation (i.e., occupational therapy and physiotherapy).

Methods

Course curriculum was developed using a blended teaching approach with a combination of online learning, lectures, team-based problem solving and client interviews. Research was completed on 247 learners utilizing a pre-post course questionnaire addressing content areas of knowledge, skills and attitude and by analyzing individual professional differences.

Results

Significant differences were found indicating improvements in student knowledge and skills for the majority of disciplines after course participation. A positive trend was found in outcome responses for student attitudinal change ranging from neutral to positive attributions about individuals with ID.

Discussion/Conclusions

This paper outlines improvements in student learning and positive attitudinal change following an educational course concerning optimal health care and collaborative practice in intellectual disabilities. It is proposed that an interprofessional blended training curriculum for future health care professionals can foster best practice and quality service for this currently underserved population.

ABSTRACTS FROM THE 2015 RSIG RESEARCH DAY THOROLD ON, APRIL 17 – POSTERS

Family Support in the Democratic Republic of the Congo: Existing Strengths and Hopes for the Future

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Background

Family support is professional help or more informal assistance that responds to families' emotional, financial, informational, and logistical needs, and is intended to enhance the quality of life of the family member with a disability and the family unit.

Objectives

This study sought to answer the questions: (a) What is a local example of an entity that provides effective and meaningful support to families who have a member with IDD in Kinshasa? and (b) what makes this support effective and meaningful?

Methods

For seven months, the senior author engaged in participant observation in the homes of families that have members with IDD, during family self-help association meetings and activities, and in the wider communities in which these families function (e.g., markets, workplaces, special schools, and physical therapy clinics often frequented by the families). We also conducted semi-structured interviews with 14 family members affiliated with family support associations.

Results

Using data from participant observation field notes and semi-structured interview transcripts, we (a) describe ANAPEHMCO, a family self-help association in Kinshasa, Democratic Republic of the Congo (DRC), (b) classify the nature of the support provided by this organization, (c) show how this support is effective and meaningful for families, and (d) discuss how associations such as the example provided can be particularly valuable for supporting individuals and families in conflict, post-conflict, or developing contexts.

Discussion/Conclusions

Families themselves are often the first creators and providers of family support in conflict and post-conflict contexts, where state priorities for family support are often low or non-existent. As nations develop and begin to structure formal state programs for family support, they would be wise to partner with families to draw upon their experiential knowledge in delivering family support.

Personal Response to Qualitative Data on Canadian and South Asian Mothers Raising a Child With a Developmental Disability

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Objectives

In the past, I (Nilani) have had many opportunities to volunteer with children with autism and I have developed an interest in learning more about autism and other developmental disabilities. For the purposes of a third-year year project course at McMaster University entitled "HTH SCI 3H03 – Inquiry," I decided to pursue a project that is related to this domain. This past year, I have assisted Nidhi Luthra with data collection and data entry for her dissertation entitled: "Experience of South Asian Immigrant and Canadian Mothers of Children with a Disability." The goal of my project is to compile and analyze my reflections and responses to the different themes I have encountered while transcribing the in-depth interview component of the study. This poster will present some themes from what the mothers said but will focus mainly on my personal responses to these mothers' stories.

Methods

"Experience of South Asian Immigrant and Canadian Mothers of Children with a Disability" is an ongoing mixed-methods study that consists of two components: a quantitative questionnaire and qualitative in-depth interviews. The data collection for this study is ongoing. Thus far, I have been able to complete reflections on 15 interviews with mothers. It is expected that there may be more interviews by April.

Results

As of now, I have been able to identify themes such as concern for the future, financial issues, struggles navigating the system, the symbiotic relationship between mothers and their children, positive and negative cultural impacts, etc. These themes have served as inspiration for my reflections and I hope to identify more themes as data collection continues. I have been both surprised and saddened by some things the mothers have expressed, but also inspired by their resilience.

Discussion/Conclusions

The poster will elaborate on the themes I have been able to identify through the data collected from the interviews and my own personal reflections and responses to these themes.

Living With A Sibling Diagnosed With Fetal Alcohol Spectrum Disorder

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Objectives

The purpose of this study is to explore the world of individuals living with a sibling who has been diagnosed with Fetal Alcohol Spectrum Disorder (FASD). More specifically, this research will be examining the relationship quality in terms of attitudes or behaviours exhibited towards the sibling with FASD and the coping mechanisms used by these siblings. Although some research has looked at siblings of children with ASD or other disabilities, to date there has been a gap in the literature regarding siblings of a brother or sister diagnosed with FASD. Studies that have examined the sibling's experience in other long term diagnoses have been inconsistent in terms of findings, with few sibling interviews conducted. Additionally, it has been reported that in adulthood, many sibling anticipate greater caregiving responsibilities of their sibling with a developmental disability as their parents age (Greenberg et al., 1999; Krauss et al., 1996) and take on the role of primary caregivers once parents are no longer able to do so (Bigby, 1997). That said, this study will allow siblings to express their concerns in order to establish where siblings are struggling and where they are flourishing in order to better tailor supports for families.

Methods

Twenty siblings without FASD will be asked to participate in a semi-structured qualitative interview through the use of art-based methods (Gauntlett 2007; Gross & Hayne, 1998), more specifically a family totem pole. This activity will shed light on family relationships while allowing art to mediate their experience as siblings of individuals with FASD. Interviews will be analyzed using the interpretive phenomenological analysis (IPA; Shaw, 2010). Additionally siblings who do not have FASD will be asked to fill out 2 scales, the Sibling Inventory of Behaviour Scale (Hetherington, Henderson & Reiss, 1999) and the Siblings Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006). These scales will be used in conjunction with the interview in a mixed methods approach to gain a better knowledge of siblings' relationship quality, coping and adaptation, as well as their daily stressors.

Results

Data collection is ongoing, so results can only be hypothesized at the time of abstract submission. Some previous siblings researchers have found that non-affected siblings report negative experiences (Neely-Barnes & Graff, 2011; Wilson et al., 1992), while other studies have found that non-diagnosed siblings look at their relationship positively (Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001, 2002). Research with parents of children with FASD have identified numerous stressors (Watson et al., 2013), but parents also speak positively about their experiences parenting a child with FASD. As our study is exploratory in nature, we expect to see a mix of both positive and negative statements related to their experience and the richness of the interview data will help to clarify this experience.

Discussion/Conclusions

This study will allow clinicians to tailor supports and provide siblings with the tools to create mutual growth and development, as they will be most likely be a long-term caregiver for their sibling with a disability.

Curriculum of Caring: A Pilot Study

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Objectives

Recent research has shown that medical students' empathy and compassion decline throughout their training, resulting in detachment, worsened medical outcomes, and increased likelihood of burnout. The following study examined whether certain educational methods stimulated students to approach and communicate more attentively and engagingly with patient educators (PEs) in a mock clinical setting, specifically PEs affected by developmental disabilities (DD). The focus on DD stemmed from the comorbidities, stigmas, and communication barriers experienced by this population, and the overall suboptimal care it receives. More broadly, the study sought to create a more positive culture around DD, and provide PEs with relevant lived experience an opportunity to participate in innovative research.

Methods

First-year students were recruited via email from the DeGroote School of Medicine (n = 27; mean age = 23.1 ± 3, [20-37]) and randomly assigned to either control or intervention groups. The control group (designed to mimic traditional, didactic methods) received an introductory lecture about caring for individuals with DD, followed by a retention-based quiz. The intervention group received the same introductory lecture, followed by two videos of individuals affected by DD talking about their lives and healthcare needs, and concluded with a reflective writing and discussion activity. It was hypothesized that exposure to and reflection upon these stories would serve as an emotional primer to foster empathic and imaginative thought, and in turn more person-centred behaviours in clinical encounters. All students then circulated through four stations, each designed around a particular PE: two with mild intellectual disabilities; a mother of a child with DD; and one affected by autism spectrum disorder and bipolar disorder. In each station, students conducted a brief (~10 minute) interview, after which they completed self-evaluations, were evaluated by the PE (and their caregiver, where applicable), and also by a third-year medical student acting as an objective rater (all using six-point Likert scales). The evaluations measured attributes such as professionalism, attentiveness, engagement, and responsiveness.

Results

Initial descriptive analyses revealed slightly higher scores in the intervention group across all measurements: self-evaluations (4.49 versus 4.37), objective rater (5.01 versus 4.75), PE ratings (5.44 versus 5.33), and caregiver ratings (5.35 versus 5.28). In addition, students in the intervention group showed greater increases in self-reported measurements of comfort (27%), competence (80%), and confidence (56%) in working with individuals affected by DD, as indicated by pre- and post-session questionnaires. The control group, in comparison, showed more modest increases (15%, 42%, and 19%, respectively). It is unclear whether observed differences are significant, as inferential analysis is currently underway.

Discussion/Conclusions

The current study found (1) more reflective, discussion-focused exposure to DD (i.e., intervention group) appeared to lead to higher performance on interviews in a simulated clinical setting; (2) marked increases in self-reported measurements of comfort, competence, and confidence following encounters with PEs; and that (3) participants consistently described their experience as meaningful and valuable. It is hoped that subsequent research could further develop these teaching models within a larger sample, as well as establish a more inclusive culture around developmental disabilities.

Fiction as a Research Method: A Short Story of Life in Residential Group Homes Used to Generate Interdisciplinary Discussion

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Objectives

Using a work of creative fiction this piece intends to challenge the dominant academic journal with its use of accessible plain language. A piece of writing born in the narrative of one person of support revolving around the impressions made in the first days of work and life in residential group homes. An honest account of experiences living and working in a supportive setting is told, and encourages its reader to engage a social model lens in review.

Methods

A short story is presented to a group of interdisciplinary students at Ryerson University of varying race, ethnicity, ability, age, and gender. The writing is used as a tool for learning, generating conversation, and carrying a disability studies framework across disciplines and experiences. This ongoing project intends to collect the discussion and feedback generated when the short story is used catalytically, to analyze and uncover the benefits of an interdisciplinary perspective, as well as the effectiveness of fiction as a method.

Results

Throughout ongoing discussions students responded positively to the approachable fictional style of writing. When engaged in discussion students from disciplines such as Child and Youth Work, English, and Early Childhood Education began to pull details from the interpretive writing. This began opening gateways to relative discussions around concepts such as social role valourization, the social model, and a hierarchy of disability. The work continues to establish pathways from the fictional short story to reference different complex disability studies perspectives to more samples of students.

Discussion/Conclusions

Using fiction as a method this work intends to bring social model understanding and disability studies subject matter across disciplines. It will examine the gains of cross disciplinary education and the benefits a social model lens presents for varying professions. The poster will present a case for fiction as a research method, the accessibility of plain language in academics, and an account of the ongoing discussions as a result.

Living With a Sibling With Autism Spectrum Disorder

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Objectives

Raising a child with Autism Spectrum Disorder (ASD) has a potential impact on the mental health and overall well-being of family members due to parenting stress (Chan & Goh, 2014; Hayes & Watson, 2013). However, children with siblings who have ASD are not frequently investigated. When siblings are researched in family studies, accounts about sibling interaction are often provided by mothers, which have shown discordance with sibling reports (Moyson & Roeyers, 2012). A recent study by Petalas and colleagues (2009) demonstrated that children with a brother or sister with ASD may have a higher risk of developing emotional and prosocial behaviour problems when compared with siblings of children with intellectual disabilities and children with typical development. Conversely, other studies have found positive effects in children with siblings with ASD (Rivers & Stoneman, 2003; Verte, Roeyers, & Buysse, 2003), such as greater affection and admiration of their brother or sister with ASD and lower levels of competitiveness and quarrelling compared to siblings who have typical development (Kaminsky & Dewey, 2001). Thus, it is important to develop a balanced investigation of sibling interactions that can explain the nature of the sibling relationship when one sibling has ASD. The purpose of this study is to obtain a greater understanding of the experiences of siblings who have a brother or sister with ASD, using a mixed methods approach.

Methods

Participants in the proposed mixed methods study will be 20 families with children who have ASD. A mixed-method approach will be utilized and consist of two questionnaires as well as an in-depth interview and arts-based methods. The Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985) and The Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2005), both reliable and valid measures, will assist in quantifying problematic behaviours and challenges or uplifts that are experienced by siblings. In the second component of the study, the researchers will gain first hand accounts from siblings about what it is like to have a brother or sister with ASD using semi-structured interviews and arts-based methods (i.e., drawing a totem pole of the family). Interviews will be analyzed using Interpretative Phenomenology Analysis (IPA).

Discussion/Conclusions

Data collection is ongoing, but this poster will provide introductory insight into the lived experience of siblings with brothers or sisters with ASD. It will convey both of the positive and negative side of these experiences, plus provide an understanding of what this experience is really like. With deinstitutionalization, many individuals with ASD are living with their families and many siblings are helping to provide supports for their siblings once their parents can no longer provide care. Therefore, this study will greatly contribute to family research and address gaps in sibling research by exploring the opportunities and challenges of children with siblings with ASD. In addition, a strength of the study is the mixed-method approach, which is often not employed in sibling research. Quantitative questionnaires can objectively measure the outcomes of sibling relationships, while qualitative methods can capture unique perspectives and personal accounts that can sometimes be lost in objective measures.

Child, Family, and Community Predictors of Child Psychosocial Functioning in a Canadian Sample of Special Olympics Athletes

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Objectives

Individuals with intellectual and developmental disabilities (IDD) often struggle with adaptive/social functioning, which relates to an individual's ability to cope with environmental demands on a day-to-day basis (The British Psychological Society, 2000). Researchers have found that individual factors, such as age (Tsatsanis, Fuerst, & Rourke, 1997), gender (Grella, 2003), ASD (Fitzgerald, 2011), and child health (Lucyx et al., 2012); family factors such as negative life events (Consoli et al., 2014); and community factors, such as school supports (Coster et al., 2013), are linked to changes in psychosocial functioning, within differing populations. However, thus far there is a paucity of research that assesses how child, family, and community factors together are related to psychosocial functioning in individuals with IDD. The purpose of the current study was to develop a greater understanding of the correlates of psychosocial functioning by examining them together in a large sample of youth with IDD.

Methods

We recruited 517 caregivers of youth and young adults with IDD registered with Special Olympics Ontario (11 to 22 years of age; M = 17.11, SD = 3.00) to complete an online or paper-pencil survey of sport participation in youth (representing 19% of registered Special Olympics participants). Child factors included ASD diagnosis, age, number of chronic health conditions, and adaptive behaviour based on the Waisman Activities of Daily Living Scale (Maenner et al., 2013). Family factors included respondent self-reported health (Roman et al., 2009), general family functioning (McMaster Family Assessment Device (Byles et al., 1998). The next factor was number of negative life events (Willemen, Schuengel, & Koot, 2010). Community factors included the community and school resources (Participation and Environment Measure for Children and Youth, community and school resource scales; Coster et al., 2012). Psychosocial functioning was measured through parents report on the Psychosocial subscale of the Pediatric Quality of Life Inventory (Varni et al., 2003).

Results

The overall model accounted for a significant amount of variance in child psychosocial functioning, based on multiple regression analysis ($F(9, 350) = 21.19$, $p < .001$; $R^2 = .34$). Significant predictors included (a) child factors (R^2 change = .12; age ($t(350) = 2.73$, $p = .007$), ASD diagnosis ($t(350) = -3.11$, $p = .002$), and the number of health conditions ($t(350) = -2.34$, $p = .020$); (b) family factors (R^2 change = .07; parent-reported physical health ($t(350) = 2.60$, $p = .010$), general family functioning ($t(350) = 2.06$, $p = .040$), negative life events ($t(350) = -2.39$, $p = .017$); and (c) community factors (R^2 change = .16; school resources ($t(350) = 7.89$, $p < .001$)).

Discussion/Conclusions

Although correlational, results of this study provide valuable information about the important role child, family, and community factors can play in the psychosocial functioning of individuals with IDD involved in community sports. Further research to elucidate the transactional relationships amongst these factors will help us better understand how to enhance psychosocial functioning in individuals with IDD.

The "Even More Basic" Level of Fundamental Movement Skills

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Objectives

Our project was based in observing and describing the fundamental movement skills of a group of teens and young adults with moderate to low functioning Autism Spectrum Disorder for the purpose of expanding and refining their movement capacities and designing progressive activities that were "even more basic" than the typical fundamental baselines associated with novice movers.

Methods

We systematically observed a group of 12 teens and young adults over a period of 18 months in both aquatic and gymnasium environments participating in gross motor, fine motor, games skills and fitness and conditioning activities. We used Laban movement theory (Maletic, 1987) to guide our observations and analysis of movement and consulted Gallahue's (1998, 2001) guidelines for fundamental motor skill development and Liu's (2012) application of motor milestones as comparative frameworks. We based our activity design in the findings of a longitudinal phenomenological analysis of movement patterns of children, youth and adults with ASD (Connolly, 2008).

Results

Our consolidated cross case comparative analyses yielded findings regarding sequencing of progressive and simplifying tasks and the necessity of both individualizing to specific movement tendencies and creating relevant movement experiences to enhance interest and adherence. In this session we hope to describe the strategies of Break it down/Build it up, station based pedagogy, and embedding under-developed (or absent) and transferable movement patterns to the design of progressions for basic skills.

Discussion/Conclusions

Many children, youth and teens with disabilities experience challenges with what might be considered "basic" skills (e.g., running, take offs, landings) not only because of neurological or developmental issues, but also because of lack of opportunity for play, participation and practice and a lack of preparation among practitioners about how to make "basic" even simpler, or progressively broken down into more fundamental elements. This paper explores the "even more basic" dimension of fundamental movement skills and uses examples and applications across a spectrum of disability, from moderate functioning to low functioning participants. The strategies will be helpful for practitioners who are working in inclusive and/or supported approaches as well as specialized and individualized programs. Additionally, practitioners may discover applicable strategies for typically developing learners who are experiencing movement challenges.

Exploring the Viability of Liaison and Follow-Up Support Models for Post-Secondary Student Development Centres

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Objectives

The purpose of this study was to examine whether liaison and follow-up support models for post-secondary student development centres could influence successful results for students with disabilities. It was believed that implementation of liaison and follow-up models that drew on students and faculty members within the institution's disciplines could complement disability staff engagement practices for students that accessed student disability centres.

Methods

This study relied on qualitative research techniques. 18 questions, 3 questions from 6 qualitative design domains including "experience and value questions, opinion and value questions, feeling questions, knowledge questions, sensory questions, background and demographic questions," were presented to 8 managers (n = 8) of post-secondary disability services offices. These managers are part of a network that is responsible to deliver support services to the 43,000 students (12.8% of the post-secondary student population) across Ontario's College and University system. 4 respondents were male and 4 were female. 5 managers represented college disability services offices and 3 represented university disability services offices.

Results

The study resulted in over 100 pages of data which was then analysed to identify common themes from the responses. The findings demonstrated that managers in both the college and university settings did not support the concept of utilizing other faculty members and students from other disciplines within their institutions to complement their respective service delivery capacity. However, the study did identify that issues related to enhanced transition planning from secondary to post-secondary education, improved faculty and student education about disability and accommodations, improved universal instructional design programs, better integrated student supports for students with Asperger syndrome and mental health needs and more inclusion efforts on and off campus were all required to help students with disability maximize their opportunities for success in post-secondary education programs.

Discussion/Conclusions

The managers had over 150 years of experience working with students with disabilities. The poster related to the study will illustrate the results of the study.

Rural and Urban Health Care Professionals' Attitudes and Awareness of Fetal Alcohol Spectrum Disorder in Ontario, Canada: A Secondary Data Analysis of the FAS Survey for Health Professionals

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Objectives

Fetal alcohol spectrum disorder (FASD) is an umbrella term that refers to a continuum of effects that are associated with prenatal exposure to alcohol. Health care professionals play a critical role in the prevention of FASD, particularly through suggestions regarding alcohol use and alcohol consumption during pregnancy, yet researchers have demonstrated that many practicing health care professionals remain under-educated about FASD. National survey results suggest that Canadian health care providers, while aware of some aspects of FASD, require further training and education to support their work of caring for both individuals at risk for having a child with FASD and for individuals with FASD and their families (Clarke, Tough, Hicks, & Clarren, 2005; Tough et al., 2005). However, the level of knowledge of FASD held by Ontario health care professionals remains unexplored.

Methods

A secondary data analysis was conducted using data obtained from the 2001-2002 Fetal Alcohol Syndrome (FAS) Survey for Health Professionals. Ontario-specific data (n = 884) was used to understand the knowledge, attitudes, and awareness of FASD held by paediatricians (n = 287), psychiatrists (n = 181), midwives (n = 68), family physicians (n = 288), and obstetricians (n = 60). Health professionals that did not indicate their medical specialty or whether they considered their practice to be urban or rural were removed from analyses (N = 834).

Results

Nearly all (99.5%) of the surveyed health care professionals had previously heard of FAS, and the majority of these practitioners either agreed or strongly agreed (92.1%) that prenatal alcohol exposure poses a significant risk factor for permanent brain damage. In addition, of the surveyed health care professionals who treat women of childbearing age, only 73.2% reported discussing the risks of alcohol during pregnancy and only 62.4% of surveyed professionals agreed with the practice of telling patients to drink in moderation. Furthermore, respondents' definition of "moderation" differed significantly based on their medical specialty. On average, family physicians considered a greater number of drinking occasions per week to be moderate (M = 3.44, SD = 2.32) compared to pediatricians (M = 2.31, SD = 1.90) and midwives (M = 2.51, SD = 2.36) ($F_{(4,788)} = 4.41$, p = 0.002). Although the percentage of health care professionals who discuss alcohol use with female patients greatly increased when those women were in a position likely to conceive (94.7%), there was also some discrepancy when it came to alcohol use during pregnancy. Only 87.9% of respondents recommended that pregnant women completely abstain from alcohol for the duration of their pregnancy. Rural health care professionals reported that they were more likely to ask pregnant women if they were currently drinking alcohol compared to urban professionals (p = .007). Rural health care professionals also reported feeling more prepared to care for biological mothers in the area of alcohol abuse or dependency compared to urban professionals (p = .011).

Discussion/Conclusions

Although the data is thirteen years old, the results of this secondary data analysis are still relevant as they support the current findings that consistent recommendations are not provided by health care professionals when advising women of child bearing age about alcohol use. This finding may be due to a lack of education regarding FASD received by health care professionals or the absence of medical guidelines surrounding this topic. Furthermore, the results of this secondary data analysis provide a starting point for understanding the knowledge and awareness of FASD in Ontario.

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Family Strengths Improve Well-Being of Family Members With Developmental Disabilities

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Objectives

Persons with developmental disabilities and their families often cope with increased health, economic, and social risks. Effective family coping depends upon the overall health of the family coupled with each family member's ability to promote positive well-being for self and others. This presentation will share findings from three family-centred studies that looked at coping strategies in unique ways. The first study examined how online self-help groups improved families' abilities to care for children with autism. The second study identified characteristics of resilience in young adult siblings of children with autism. The third study outlined positive coping abilities in parents who were caring for adult children with developmental disability and mental illness who lived at home. Overall, these studies examined which family strengths may promote the well-being of both caregivers and members with developmental disabilities.

Methods

The studies used semi-structured interviews to explore a) self-help group experiences of 22 parents of children with autism, b) resilience characteristics of 14 young-adult siblings of children with autism, and c) coping abilities of 15 parents caring for adult children with dual diagnosis. Research participants were recruited through notices distributed at local agencies and by word of mouth. Interviews were analyzed using qualitative techniques in which the researchers assigned codes and categories to significant statements in a line-by-line examination of the transcripts and then identified common themes across participants.

Results

Overall, the three studies suggested five areas of family strengths which positively impacted families and family members with developmental disabilities. First, the ability to see positive aspects of disability improved family coping and supportive family relationships for family members with developmental disability. Second, close family relationships provided support for parents, siblings, and family members with developmental disability. Third, ability to access resources, such as financial, educational, and residential care options, decreased the stressful impact on all family members. Fourth, supportive relationships with friends, extended family, and from self-help groups improved family members' coping ability, which in turn improved supportive relationships between caregivers and family members with developmental disability. Fifth, the ability to effectively advocate for needed services and to educate public and professionals about developmental disabilities improved caregivers' efforts.

Discussion/Conclusions

These findings support interventions that enhance family strengths in order to improve the well-being of persons with developmental disability across the life span. Specifically, positive outlooks about disability and emotionally supportive relationships serve to improve family coping skills and by extension families' ability to provide instrumental and emotional support for members with developmental disability. Siblings need emotional support from parents and supportive relationships with friends are particularly important for adolescent siblings. Nurturing family relationships improve coping for all family members, as do supportive relationships outside of the family, including self-help groups. Enhancing parents' ability to access, advocate, and educate the general public and service professionals about needed resources can increase supportive relationships and services which improve the quality of life for persons with developmental disabilities and their families. Although small sample size limits generalizability, finding common elements in three different studies strengthens the findings.

Using Visual Search Strategies to Understanding Intermodal Perception in Children With an Autism Spectrum Disorder

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Objectives

Children with Autism Spectrum Disorder (ASD) experience difficulty when processing information from more than one sensory modality (Iarocci & McDonald 2006), compared to typically developing children, and this difficulty is particularly evident in the processing of linguistic information (Bebko, Demark, Weis, & Gomez, 2006). However, linguistic information is inherently social and it is a challenge to separate the social aspects of an event from the linguistic aspects of an event; therefore, while children with ASD do demonstrate a deficit in processing intersensory linguistic information, it is unclear whether the cause of the deficit is a result of the linguistic nature of the information or the social nature of the information. To address this question, the current study assessed visual processing strategies in groups of children presented with audiovisual stimuli and manipulated the language and social content.

Methods

Participants included 20 children with ASD and a control group of 20 children with typical development ranging in age from six to 16 years. The participants viewed a presentation screen displaying four identical videos in each of the four quadrants. The videos in each trial had differing levels of linguistic and social content. While the participants completed the task, an eye-tracking device recorded eye movements. For the present study, a coding scheme was constructed to categorize eye movements as either "efficient" or "inefficient." Eye movements were categorized as "efficient" if participants fixated at areas of the task that provided meaningful information. For example, in a video with linguistic content, a fixation on the mouth would be categorized as "efficient." Furthermore, eye movements were categorized as "inefficient" if participants fixated at areas of the task that did not provide meaningful information. For example, a fixation on the black background of a task would be categorized as "inefficient." Once the eye movements were categorized, the amount of "efficient" and "inefficient" gaze shifts between groups were compared across stimuli.

Results

Preliminary analysis ($N = 33$) revealed a significant main effect of group, such that the TD group used more efficient visual search strategies to process the stimuli compared to the ASD group, $F(1, 31) = 6.94$, $r = .18$, $p = .013$. There was no significant main effect of trial type, and no interaction between group and trial type (all $ps > 0.05$).

Discussion/Conclusions

The findings of differences in efficiency of intersensory processing for social and linguistic information in children with ASD is an important finding as it helps clarify where some of the intersensory difficulties may be in ASD.

Adults With Cerebral Palsy: Characteristics and Health Issues

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Objectives

Cerebral Palsy (CP) is the most common cause of complex and physical disability in childhood. Previous literature has shown that individuals with CP experience comorbid physical and mental health issues, as well as low life expectancy. It is not well understood what demographic and clinical variables are associated with the presence of specific physical and mental health issues among persons with CP, with and without a developmental disability (DD). Using large administrative health databases, the current research aimed to identify adults in Ontario with CP with or without DD, and to describe their characteristics and comorbid physical and mental health issues.

Methods

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and wellbeing of individuals with DD through improved healthcare policy and improved services. H-CARDD created a cohort of adults (ages 18 to 64) with CP from administrative health databases consisting of regularly collected records from physician visits, hospitalizations, and emergency department visits. For comparison we also created 2 groups: (1) Ontarians with DD (excluding CP); and (2) a random sample of the general Ontario population (excluding DD and excluding CP). The three groups were described and contrasted on demographics, and mental and physical health comorbidities.

Results

14,155 adults with CP were identified from the Ontario health databases; of these 33% also had a DD. Persons with CP had demographic patterns similar to comparison group of Ontarians with DD. When compared to the general population, individuals with CP were younger and more likely to be male. Consistent with findings among Ontarians with DD, adults with CP were more likely to have a psychiatric comorbidity than the general population. Asthma was the most common physical health condition in persons with CP, with a higher prevalence than what was found in those with DD, and the general population.

Discussion/Conclusions

This research successfully used administrative health data to identify and describe the demographics and health status of adults in Ontario with CP. These results can be used to inform health and social service providers and help to guide policy development for adults with CP.

Performance Validity Tests and Autism Spectrum Disorders: An Early Investigation

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Objectives

There is a growing evidence for the use of performance validity tests (PVT) with children during neuropsychological testing. The literature supports the use of adult PVTs in children with a variety of medical and neuropsychiatric diagnoses. However, there is a paucity of literature examining whether it is appropriate to use PVTs with children on the autism spectrum disorder (ASD). The current study examines PVT profiles in a sample of children with ASD to identify factors that may explain PVT failures.

Methods

Data were collected from 43 children (91% male) with ASD referred for neuropsychological assessment. Mean age was 12.1 years (SD = 3.7, range: 5-19). Mean FSIQ was 84.3 (SD = 84.3, range: 46-124), while mean PPVT-III score was 100.7 (SD = 21.1, range: 51–134). Performance validity was assessed using the Green family of PVTs: Word Memory Test, Medical Symptom Validity Test and Non-Verbal Medical Symptom Validity Test. Adaptive functioning was measured using the Behavior Rating Inventory of Executive Function (BRIEF).

Results

While the majority (81%) of the sample had no PVT failure, 8 out of 43 children failed at least one. PVT failure was associated with being younger, lower cognitive functioning and paradoxically, fewer executive deficits on the BRIEF.

Discussion/Conclusions

The poster will discuss the implications of these results to interpreting cognitive data in diagnostic considerations and the limitations of the use of PVTs in children with ASD. Also, the puzzling relationship between PVT failures and BRIEF scores will be discussed.

Encouraging Adults With Intellectual and Developmental Disabilities to Have an Annual Health Check-Up – Not as Simple as it Seems

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Objectives

Annual health check-ups lead to early identification and treatment of undiagnosed conditions, and aid in the prevention of more complex health problems among adults with intellectual and developmental disabilities (IDD). Despite the evidence of these benefits, adults with IDD attend an annual health check-up less frequently than the general population. Self-referral is the primary way patients attend the annual health check-up, therefore, to improve attendance it is crucial to engage patients/caregivers. The purpose of the ongoing multi-phase study is to explore the effectiveness of an intervention to increase uptake of annual health check-up by adults with IDD. The poster will focus on the first phase and will examine how accessible the intervention is to this population.

Methods

A population-based intervention was implemented, which aimed to increase uptake of the annual health check-up by adults with IDD. An accessible language information package was sent in the last week of October 2014 to individuals with IDD who are Ontario Disability Support Program recipients (N = 39, 868). The package included details about the annual health check-up, its importance, instructions on how to book an appointment, and a link to a video of the written information in the mail out. It also included researcher contact information and instructions to take part in a voluntary phone interview regarding the intervention package and the annual health check-up. Data collection is ongoing. To date, 153 participants have taken part in the telephone interview, including 72 (47%) proxies who responded on behalf of the adult with IDD and 81 (53%) adults with IDD. Adults with IDD (who participated themselves or for whom a proxy participated) range from 22 to 68 years of age (M = 39.76, SD = 12.22). There are 81 (53%) male adults with IDD, 71 (46%) female persons with IDD, and 1 (1%) person who did not identify as male or female.

Results

Of the 39,868 information packages that were mailed out, 1,233 (approximately 3%) were returned as undelivered. To date, there have been 133 visits to our website (for which the link was provided in the information package) and our information video was viewed 123 times. Four hundred and seven people contacted the research team about the study. From the individuals that contacted us 153 (37.6%) have taken part in the interviews. In the poster we will be exploring demographic differences (e.g., age, gender, and living situation) between individuals with IDD who read the information package themselves (55%) and those who had it read to them (45%). We will also examine the differences between the persons with IDD who found the information easy to understand (60%) and those who did not (40%).

Discussion/Conclusions

Findings from this study will provide essential information regarding the accessibility of a health education intervention via mailing of information. This information will allow for the development of accessible and effective interventions to increase uptake of the annual health check-up and possibly specific disease screening among adults with IDD, ultimately leading to enhanced overall health for persons with IDD.

Respite Care for Children With Intellectual Disabilities: Perceptions of Need for Pain Training and Preferences

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Objectives

Inadequately managed pain among children with intellectual disabilities is a common problem, which is likely due to challenges in effectively communicating their pain to others, including providing pain self-reports of their pain (Chen-Lim et al., 2012; Dubois et al., 2010; Twycross & Williams, 2013). Thus, caregivers often play an important role in assessing these children's pain (Breau et al., 2003). Respite caregivers are common non-custodial caregivers of children with intellectual disabilities, and the importance of respite care as support for these children's families continues to grow (Chan & Sigafoos, 2000). Research conducted by Genik, McMurtry and Breau (in preparation) found pain training to be quite uncommon among respite caregivers in their sample (5/54 respite caregivers). Further, some pain-related beliefs held by these caregivers (e.g., the ability of children with intellectual disabilities to sense pain) were inconsistent with current research. The objective of this study is to gather information about perceived pain assessment and management training needs from both front line and management staff in organizations which provide respite care services to children with intellectual disabilities.

Methods

Participants consist of (1) active respite caregivers and (2) respite care management staff employed in organizations providing children's respite services. As part of a larger study, respite caregivers and management completed a brief 15 item researcher-generated questionnaire. This measure gathers information on a number of topics such as: (1) interest in, applicability of, and importance of pain training programs (statements with scaled rating responses; 0 = "Strongly Disagree"; 10 = "Strongly Agree"), (2) training program format preferences (rank order selection, e.g., in person versus online training, length of training), and (3) preferred topics to include (open-ended responses).

Results

Data collection is 90% complete; data analysis will be completed by the end of March. Responses from respite caregivers will be analyzed separately from responses from management staff. All scaled rating and rank-ordered questions will be analyzed using frequency analyses. For example, means and ranges will be used to describe ratings of perceived importance of pain training programs. The five open-ended questions will be analyzed through content analysis. The researcher will begin by reviewing each open ended question. In collaboration with a primary investigator, coding categories will be developed using open coding and inductive methods. This coding scheme will then be refined, and two additional coders will be trained to use the scheme. Cohen's Kappa will be used to calculate reliability between coders, and discrepancies will be resolved amongst the coders and primary investigators. Following completion of coding and adequate reliability, frequency analyses will be used to further explore the data.

Discussion/Conclusions

This poster will provide novel data on respite caregiver and management staff's perceived pain training needs in working with children with intellectual disabilities. Limitations and implications of the results will be discussed in the context of this program of research; the next phase is to incorporate these results in combination with extant research literature to develop and pilot a pain training program designed for respite caregivers.

Knowledge About the Diagnosis and Treatment of Children With ASD: Perspectives From Medical Professionals and Teachers

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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' 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). Educational and 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 month of age, they do not receive a diagnosis until the age of 3-4 years (Rhoades, Scarpa, & Salley, 2007). As Rhoades, Scarpa, and Salley (2007) suggested, many health care providers feel incompetent in both the assessment and diagnosis of ASD. The purpose of this research is to investigate the knowledge of educational and health care professionals regarding the diagnosis and treatment of ASD in Ontario.

Methods

Participants will be medical practitioners, nurses, and teachers in Ontario. My research will employ a two-phase, mixed methods approach. During the first phase, participants will fill out a questionnaire regarding their knowledge and attitudes about ASD. The second phase will incorporate semi-structured interviews, in which participants will be asked to answer questions with regard to their knowledge about the identification, diagnosis, and treatment of ASD, as well as their attitudes and approach about ASD. The participants will also be asked about their experiences of working with this population.

Results

The results of this study are pending as the data collection will be undertaken during the months of June and October, 2015.

Discussion/Conclusions

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

Self-Reported Instructional Competence and Confidence in Parents of Teens Diagnosed With Autism Spectrum Disorder: An Analysis of the Relationship Between Competence, Confidence and Related Factors

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Objectives

The aim of this research study is to explore the theoretical and applied implications for the delivery of provincial ABA programs, increase knowledge within Kerry's Place about parent perspectives on competence (i.e., instructional control) and confidence and gather information on areas most in need of training. Researchers hypothesize that parent levels of competence are directly correlated with parent levels of confidence.

Methods

This study included 52 parents of youths diagnosed with ASD, ages 11-18 who were currently receiving services at Kerry's Place Toronto ABA sites. Each parent completed the Self Reported Levels of Competence and Confidence Parenting Questionnaire. Questionnaires contained 11 questions in multiple choice format, 8 on parent competence and 3 on parent confidence levels,. Data resulting from individual questions were put into Statistical Package for the Social Sciences (SPSS). An Analysis of variance (ANOVA) was used to examine the effects of Number of sessions (i.e., groups), youth's level of functioning, type of curriculum, and location of program delivery. Finally, the overall results were analyzed.

Results

A series of ANOVAS revealed that the level of functioning, family size, age and location of the program had no significant effect on parent levels of competence or confidence. Parents of children exposed to a greater number of groups showed greater competence in their parenting skills. Parents of boys were found to be more competent than parents of girls. Parents of youth exposed to the Social curriculum had greater competence than those exposed to other domains. Parents exposed to a greater number of sessions and parents of boys showed a greater level of confidence for one of the questions. Consistent with the researchers' prediction, an inter correlation matrix determined that, for many of the questions, competence and confidence were highly correlated. Greater levels of instructional control in the form of parent follow through correlated with increased overall parent confidence, and specifically with confidence in managing their youth in the community. Higher levels of parent instructional control in the form of presenting quality instructions inversely correlated with lower levels of worry about giving instructions. Higher levels of gaining appropriate attention inversely correlated with lower levels of worry. Finally, higher parental confidence levels in managing their youth in the community correlated with greater overall parent confidence.

Discussion/Conclusions

This study confirms that self-reported parent competence and confidence levels directly correlate. That parents of youth who attended higher number of previous sessions reported higher levels of competence and confidence naturally follows since the youth had more educational opportunities. Similarly, parents of youth attending more sessions may have had more training. Parents of youth who attended the Social group were more competent and confident. This may be a result of youth having more adaptive and communication skills (i.e., prerequisites for the group). Results also demonstrated that increased confidence directly correlated with increased competence, specifically to gain youths' attention, deliver higher quality directions and to better follow through with original instructions. Further research is recommended focusing on building parents' level of instructional control within the community.

Using a Behavioural Skills Training Approach to Teach Parents Instructional Control Will Increase Parent Confidence in Delivering Instructions and Overall Confidence Levels

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Objectives

The aim of this research study is to fill a research gap which appears to exist regarding levels of instructional control and confidence for parents of adolescents. This study examined self reported levels of competence (i.e., instructional control) and confidence of parents with adolescents diagnosed with ASD, 11–18 years old, before and following a Four-Phase Behavioural Skills Parent Training model in gaining instructional control. Researchers hypothesized that there will be an overall increase in self-reported levels of competence and confidence following the Four-Phase Behavioural Skills Training package.

Methods

This Pre-Test/Post-Test design consisted of 5 parents of youth aged 11–18, currently enrolled in Kerry's Place Autism ABA Services. These parents reported low levels of instructional control and confidence in the previous Parenting Perspective Questionnaires created by the same authors. Researchers administered a Parenting Perspective Questionnaire pre-test. Parents then participated in a Four-Phase Behavioural Skills Training: (1) Parent Didactic Workshop, (2) Video Modeling and Role Play, (3 & 4) Individual Parent/Child Coaching Sessions. BTs took data while one of them also coached the parents and provided feedback on their performance, when necessary. The Parenting Perspective Questionnaire was re-administered as a post-test to determine possible changes in their view of their abilities to manage their child's behaviour. Results were then scored and analyzed.

Results

Results from the Pre-Test/Post Test Questionnaires showed an overall increase in self-reported levels of competence and confidence at the completion of the study. Specifically, 80% of parents reported an increase in gaining attention prior to delivering an instruction. In Question 2, 60% of parents reported an increase in delivering concise instructions one time only. In Question 3, 60% parents relayed an increase in getting follow through with instructions. Question 4, 80% of parents reported an unchanged level of worry about giving instructions. In Question 5, 40% of parents reported increased confidence in managing their youth's behaviour in the community. Finally, in Question 6, 80% of parents reported an increase in their overall confidence levels. After parents completed Phase 2 of training, data were taken using the Instructional Control Component Checklist. IOA data were collected for 90% of the sessions. Mean IOA was 98.9% (range was 96%–100%) across the 5 participants.

Discussion/Conclusions

This research study demonstrated that providing didactic instruction combined with a BST model for training instructional control to parents of youth aged 11-18 diagnosed with ASD, correlated with increased levels of parent competence. The parents' self-reported levels of both competence and confidence were corroborated by data from the Pre-Test/Post-Test Questionnaire. Additionally, through evaluation forms given out at the start of Phase 3, as well as parent oral reports, parents reported that the information taught was very useful and helpful in their current managing of their children. This study focussed on increasing instructional control with simple one-step instructions. Future studies may wish to include teaching simple one-step instructions directly in the community, as well as teaching multiple-step instructions.

Canadian Parents' Journey to Obtaining a Diagnosis: Current Challenges and Areas of Support

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Objectives

Obtaining a clear and timely diagnosis can be very confusing, difficult, and stressful for parents of children with developmental disabilities (DD). This experience may be even more challenging when the child has Autism Spectrum Disorder (ASD). Although the current literature suggests that the overall diagnostic process is a negative experience for parents (Mansell & Morris, 2004; Osborne & Reed, 2008; Siklos & Kerns, 2005), few cross-Canada studies have been conducted. The aim of this study is to investigate the parents' perspective of the diagnostic process as a function of child characteristics (severity of DD, diagnosis of ASD) and demographics (SES, location, immigrant status).

Methods

Data comes from the Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) Extended Survey which was completed online or paper by 208 parents (91.5% biological mothers) of children with severe DD (71.6% boys) aged 4-19 (M = 11). 122 children (58.7%) had ASD in addition to severe DD. This nationwide survey included questions focusing on the diagnostic process parents had gone through, latency from when they were first concerned to the initial diagnosis, how many and what sorts of professionals were involved, and how satisfied parents were with the process. Qualitative analyses were used to study parents' responses to an open-ended question regarding their experiences in obtaining a clear diagnosis.

Results

In our sample, parents of children with ASD reported a later age of first concern ($X^2(2,203) = 38.34$, $p < 0.001$, $V = 0.44$) and a later age of diagnosis ($X^2(4,204) = 53.85$, $p < 0.001$, $V = 0.51$) than parents of children with other DDs. However, children with other DDs were less likely to obtain a definitive diagnosis. SES, community size and immigrant status were not found to be related to parent ratings of difficulty in obtaining a diagnosis. Preliminary qualitative analyses revealed that the lengthy waiting time to obtain a diagnosis, compounded with seeing multiple doctors and undergoing various assessments, lead many parents to feel frustrated. Early communication about expectations and parent-professional collaboration contributed to a more positive parent experience.

Discussion/Conclusion

Although it is expected that certain disorders would be diagnosed at birth and others later on in childhood, the waiting time for diagnoses and number of professionals seen before obtaining a clear diagnosis is cause for concern. Findings indicate that despite these challenges, some parents report positive experiences. In order to increase positive parent experiences with the diagnostic system, building a strong parent-professional relationship should be emphasized.

Participation, Self-Advocacy and the Convention on the Rights of Persons With Disabilities for Transitional Age Youth

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Objectives

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that individuals with disabilities, specifically intellectual disabilities in this case, have a right to meaningful employment, community involvement and a right to education including higher education. In order to be able to ensure that these rights are enacted persons with disabilities need effective self-advocacy skills. The purpose of my research will be to see how self-advocacy skills and rights knowledge can better prepare youth with intellectual disabilities for the transition from high school to post-secondary education and training and to work. The literature states that youth who have good self-advocacy skills are better equipped to engage in effective self-determination giving them the ability to select personal goals, plan steps to achieve these goals, and to assess their progress toward goal attainment (Kleinert, Harrison, Fisher, & Kleinert, 2010). When children and youth are taught self-advocacy skills they are more likely to have a better quality of life and are more likely to challenge others who see them as incapable (Kleinert et al., 2010; Test, Fowler, Wood, Brewer, & Eddy, 2005). When making choices regarding their future it is important for youth with intellectual disabilities to see choices as meaningful, they must understand the options from which they are choosing and also understand the personal consequences that will come from each option (Fyson & Cromby, 2013). However these steps are not always ensured when they are making choice for themselves. The focal research question of this project is: How can the teaching of self-advocacy skills give youth with intellectual disabilities the tools to actively participate in decisions affecting their future, and what type of self-advocacy skills are needed to do so as seen by professionals working with Transitional age youth with ID and parents of transitional aged youth with ID?

Methods

I plan to interview 5–10 professional informants and 5–10 parents of individuals that have intellectual disabilities within the transitional aged youth stage. These will be semi-structured interviews that will be of one hour in length. Within and across group thematic analyses will be conducted on the interviews from these interviews.

Results

The results of this study are pending as the interviews will be undertaken in January–February 2015.

Discussion/Conclusions

The findings of this study will have real world application in that it will help to better understand the self-advocacy skills individuals with intellectual disabilities need to be better equipped to transition out of high school and better self-advocate for their choice. Whether this choice will be further education, community involvement or the work place, self-advocacy skills can be taught to them to better help them in this environment as they have right to each option. The self-advocacy skills that are identified by the study participants as being most helpful for individuals with intellectual disabilities to be better equipped to participate in this transition will be used in a follow-up study to examine effective self-advocacy education strategies for youth.

A Comparison of Sibling Relationships in Families of Children With Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder

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Objectives

Disabilities are becoming increasingly prevalent, and like the general population, individuals with disabilities are also experiencing increased life expectancy due to medical advances and improved living conditions (Heller et al., 2010). Since the deinstitutionalization movement, 60 percent of individuals diagnosed with a developmental disability (DD) are currently living at home with their parents and caregivers (Abrams, 2009; Hodapp et al., 2010), and due to this increased prevalence, future planning becomes imperative. Studies have shown that it is often a sibling who takes on the support and caregiving role in the life of a person with 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 Autism Spectrum Disorder (ASD) and to the researcher's knowledge, no studies investigating siblings of children with Fetal Alcohol Spectrum Disorder (FASD). Differences in the behavioural challenges posed by children with ASD 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, supports can be tailored to help lighten their experience.

Methods

As part of a larger mixed methods research project examining the experiences of families raising children with ASD and FASD in Ontario, Canada, this study will involve collecting, analyzing, and integrating both qualitative and quantitative data (Teddlie & Tashakkori, 2009). A total of forty families from the province of Ontario that have both a child diagnosed with either ASD or FASD and at least one sibling without a disability will be recruited. In-depth, semi-structured interviews will be conducted, which will be informed by a basic interpretive approach (BIA) (Merriam, 2002). Participants will also complete a number of quantitative questionnaires, including the Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2002, 2006) and the Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981; Hetherington, Henderson & Reiss, 1999)

Results

Data collection and analysis is currently ongoing. Results will be available for this presentation.

Discussion/Conclusions

The results of this study will provide an understanding of the lived experiences of siblings living with brothers and sisters who have been diagnosed with ASD and FASD. Results of this study may also be helpful in developing and implementing appropriate supports for siblings of children with DD. Limitations and directions for research will be discussed.

The Effects of Family Relationships While Raising a Child With Autism Spectrum Disorder

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Objectives

Families can experience numerous challenges while raising a child diagnosed with an Autism Spectrum Disorder (ASD), and family dynamics and coping techniques can either promote or impede relationships among family members. While research has been conducted on caregivers, few studies have considered the effects of caring for a child diagnosed with a disability on the child's siblings. This study attempts to increase the literature on the effects of family dynamics and coping mechanisms on family relationships while raising a family member diagnosed with ASD. A focus is placed on the family challenges and experiences that occur as their family member is transitioning to Adulthood. Such research is essential as an increasing number of children are being diagnosed with ASD.

Methods

Material for this study was obtained through detailed, qualitative interviews of young adults diagnosed with ASD. Their caregivers and siblings were also interviewed. Participants consisted of five families (caregivers N = 7; individuals diagnosed with ASD = 5; siblings = 4). All of the interviews were directed by experts in the field of Autism, and the interviewers allowed the participants to select their preferred interview location. The interviews were audio-taped and were later transcribed and analyzed for relevant quotations and common themes.

Results

Findings from the interviews demonstrate that supportive family dynamics are an essential factor in family resilience. Caregivers who engaged in mutual positive support and communication with their partners expressed greater coping abilities than caregivers who revealed a lack of support from their partners. Additionally, gender appeared to influence the methods of support that caregivers provided for their child diagnosed with ASD. Female caregivers were more likely to focus on researching and obtaining resources and supports for their children, while male caregivers focused on providing emotional and financial support. Siblings of children diagnosed with ASD frequently expressed resentment and jealousy of the amount of attention and resources their sibling received, particularly if their sibling was diagnosed on the lower end of the autism spectrum. However, all siblings also identified positive facets of growing up with a sibling with ASD. Participants also revealed a lack of resources which focus on assisting siblings and male caregivers of individuals with disabilities.

Discussion/Conclusions

The interviews reveal that caregiver resilience was impacted by the levels of support and communication that partners engaged in. Additionally, findings also indicate a need for greater supports for siblings and male caregivers of individuals with ASD, particularly with an increasing number of individuals diagnosed with ASD. Individuals in the field of Social Work and Mental Health can meet these arising needs by facilitating male-oriented and sibling-oriented support groups and by providing additional resources focused on those particular demographics.

DD Cares: What is the Experience of Staff Involved in an Initiative to Improve Emergency Care for Patients With Developmental Disabilities?

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Objectives

The Sunnybrook Health Sciences Centre Emergency Department (ED) implemented an initiative to improve care for patients with developmental disabilities (DD) called DD CARES. The process seeks to improve staff awareness of patients with DD and provide staff with support and strategies during the patient's ED visit. This study collected data during the first year of implementation and aimed to assess the following dimensions: (1) staff awareness of the initiative; (2) how the initiative fit within current practices; (3) burden of the initiative on staff time; 4) access to ongoing support and training opportunities; and (4) impact on care provided to patients with DD. The goal was to use staff feedback to modify the DD CARES process throughout implementation, optimize the efficacy of the initiative, and to enhance patient care.

Methods

Following involvement in the care of a patient with developmental disabilities, ED staff were asked to complete a brief follow-up survey. The survey assessed fit and burden of the initiative, ongoing training and support opportunities, and how they felt the process impacted patient care (modified from the expanded evidence-based practice scale by Aarons et al., 2012). Later, questions specific to the staff member's role in the DD CARES process were added. The survey was completed by 35 respondents, and the additional questions were completed by 14 respondents.

Results

Preliminary results suggest that all staff were aware of the DD CARES initiative and its purpose. In terms of fit and burden, respondents largely felt the process fit with their clinical approach (94%), and most (83%) indicated they were receptive and had time to implement the initiative. In terms of organizational support, most respondents (79%) felt that sufficient training and opportunities to learn about DD CARES had been provided. The majority (80%) of clinical care leaders (CCL) reported that they had printed and attached tip sheets to patient charts, however less than one third (29%) of physicians or nurses indicated they had viewed these tip sheets. Almost all (91%) respondents felt that DD CARES had a very positive impact on patient care for this population.

Discussion/Conclusions

Preliminary findings suggest that ED staff were aware of the DD CARES initiative, and felt they had the time and opportunity to learn about and implement it. Critically, staff also felt the process improved patient care for individuals with DD. Gaps reported in some of the processes suggest further improvement to the process may be needed to facilitate communication among ED staff members so that care is optimized. Improved care for individuals with DD may prevent repeat ED visits for same/similar problems.

From Research Into Practice: Identifying Non-Pharmaceutical Treatment for Students Living With Concussion and Mild Injuries to the Brain

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Objectives

Cognitive, affective and physical symptoms affect a significant minority of persons whom have sustained a mild head injury (MHI; i.e., concussion). Since MHI in children 17 years old and younger accounts for 10% of all hospital admissions (e.g., Schneier et al., 2006), addressing sequelae of MHI is of significant priority within the educational system, as this environment is optimal for implementation of rehabilitation strategies. Therefore, translation of evidence-based rehabilitation and psychoeducational strategies designed to identify effective treatments for reducing the constellation of symptoms experienced by this population into clinical practice is important. There is a paucity of evidence regarding novel non-pharmacological treatments for MHI symptom reduction. Recently, there has been increased interest in the investigation of the psychological construct of mindfulness and its role in clinical intervention. While there are various conceptualizations of mindfulness, most working definitions describe mindfulness as non-elaborative, non-judgmental, present-centered awareness on each thought, feeling, or sensation (Bishop, 2004; Kabat-Zinn, 1900). Overall, mindfulness has to do with universal human qualities of attention and awareness and systematically developing these attributes is can lead to improved psychological health. Empirical literature has identified mindfulness as a potential avenue for the treatment of individuals suffering from chronic and acute MHI symptoms and a review of this literature on MHI and mindfulness could further support and promote efforts to investigate the benefits of mindfulness for persons suffering from heterogeneous MHI symptoms.

Methods

A systematic review of the literature was performed examining evidence that observed benefits of mindfulness in clinical and non-clinical populations with specific focus directed toward the brain injury population. This review begins with a description of the construct of mindfulness. Next, observations from cross-sectional and longitudinal studies supporting mindfulness in clinical and educational settings were reviewed. This evidence was supported through neural imaging studies examining potential mindfulness-related neurological changes mediating observed benefits. Finally, studies observing the benefits of mindfulness in brain injury and pediatric populations were discussed along with potential future research.

Results

There exists voluminous evidence supporting benefits of mindfulness in clinical and non-clinical populations. Randomized controlled trials have found clinically significant benefits of mindfulness interventions in improving a constellation of symptoms including depression, reducing the propensity for stimulus over-selectivity, reducing mental fatigue and improved overall psychological well-being. Mindfulness interventions have also observed improvements in self-report quality of life, self-efficacy and increased social problem solving skills. Qualitative data has indicated that participants, even those very skeptical of the treatment, found it to be life changing and very beneficial.

Discussion/Conclusions

Overall, evidence suggests that when one learns to allocate attention and cognition mindfully, it is a clinical efficacious rehabilitation strategy for head injury populations. Mindfulness skills can be easily adapted to various immediate contexts (e.g., the classroom, the playing field), and have a positive impact on overall psychological and physical health.

Predictors of Emergency Department Staff's Perceived Readiness Working With Individuals With Developmental Disabilities

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Objectives

DD CARES is a program designed to improve the care of individuals with developmental disabilities (DD) in primary and emergency care settings. Two emergency departments in different regions of Ontario took part in the DD CARES intervention beginning in fall 2014, which included educating emergency department (ED) staff on strategies for treating adults with DD. As part of implementing this practice change initiative, we plan to evaluate the effectiveness of this component of the DD CARES intervention using pre- and post-surveys of ED staff. There were three objectives to this evaluation: 1) to measure attitudes, emotions, comfort level, and perceived skill of health care providers in providing care to individuals with DD before and after the intervention, 2) to measure readiness for change before the intervention, and 3) to determine if there was any change in attitudes, comfort level, and perceived skill of health care providers.

Methods

A one-page quantitative survey to measure the comfort, skill, attitudes and emotions of ED staff in providing care to individuals with DD, was developed for delivery at emergency departments at implementation sites. At both sites, surveys were delivered individually to ED staff by an internal facilitator to ensure a representative sample. Quantitative survey items were measured on 3-point (skills) and 5-point (comfort level) Likert scales. Due to small sample sizes at each location, 5-point scales were collapsed. Response frequencies for each question were generated and compared between intervention sites. Differences in scores between sites will be tested for statistical significance using the Mann-Whitney U test. Follow-up surveys will be collected in March 2015 at the end of the intervention time period. Pre and Post data will be compared within and across sites once data has been collected.

Results

Seventy-nine surveys were collected at site one, and 22 at site two. The majority of respondents at both sites were registered nurses (64.56% and 86.36%). Preliminary results demonstrate that the majority of staff at both sites feel comfortable discussing disability with a patient or caregiver (77.63% and 57.14%). However, the majority of staff at both sites (49.35% and 36.37%) indicated that they were not equipped with the proper resources to make desired accommodations, and most staff (53.33% and 59.09%) were unfamiliar with local community resources for individuals with developmental disabilities. Moreover, when asked to choose the statement that best described their interest in implementing DD CARES at their site, less than half of the ED staff said that they plan to be involved in implementing DD CARES tools in the department (47.14% and 31.82%).

Discussion/Conclusions

Preliminary findings suggest that most staff feel fairly positive about their ability to care for individuals with DD, but that there is room for improvement in staff awareness of community resources and a need for more resources to make accommodations. The post-survey will allow the measurement of change in staff comfort, knowledge, attitudes and perceived skills, after receiving the intervention and after having the opportunity to adapt their care.

What Factors Influence the Health of Older Adults With Developmental Disability in Northern Ontario?

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Objectives

A number of studies from a Southern Ontario perspective have demonstrated that individuals with developmental disabilities (DD) have lower participation rates in cancer screening as well as higher rates of obesity (Cobigo et al., 2013) which increase onset of diabetes and cardiovascular illness. In addition, researchers state that mortality and morbidity rates in the DD population exceed mortality and morbidity rates for the general population (Ouelette-Kuntz et al., 2005), plus poverty and rurality decrease screening rates. However, empirical research on the health of individuals with disabilities from a Northern Ontario perspective does not exist. The current study will provide evidence based information to outline the factors that influence health outcomes for adults with DD in the 45 to 65 age bracket.

Methods

The proposed research project will employ a mixed methods approach, informed by the Social Determinants of Health Theory. The quantitative component will duplicate the methods employed from Southern Ontario studies (Balogh et al., 2014; Cobigo et al., 2013) that compared DD participation rates in health screening assessments and engagement to those adults in the general population. The qualitative component will employ purposeful sampling with older adults with DD who live independently or with family/associate families and will include dyadic/multiple interview techniques. The interview questions will elicit data regarding the presence of a family physician and dentist; nature of engagement; referral protocols and information that is gathered during those engagements (e.g., BP, weight, diet). The study will also examine how factors related to the Social Determinants of Health (e.g., poverty, education rurality) may impact engagement and screening rates of older adults with DD.

Results

The results of this study are not yet available as data collection has not yet begun. Informed by results from similar studies, (Conlon et al., 2010; Lightfoot et al., 2010) addressing health disparities in the general Northern Ontario population, expected results from this research are that the health status for individuals with DD from Northern Ontario will exceed Southern Ontario mortality and morbidity rates. It is anticipated that the qualitative component of the research will identify and demonstrate what factors (e.g., the presence of a family physician, quality of engagement with the physician, extent of referrals for health assessments, cancer screening examinations) influence lower health status for the DD population. This information is necessary to help identify gaps in health service delivery to adults with DD so that best practices can be developed. Once the information is identified, it will be shared with individuals, families, medical and dental practitioners and agencies that support people with DD to improve health outcomes for individuals with DD across Northern Ontario.

Cognitive-Behavioural Therapy (CBT) for Treating Anxiety Among Children With Intellectual Disabilities: A Literature Review and a Proposal

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Objectives

Anxiety is one of the most commonly reported problems among children with intellectual disabilities (ID). Yet, to date, few evidence-based anxiety treatment protocols have been developed that take into consideration the developmental needs of these children. The present project was undertaken to survey the current CBT literature in order provide some recommendations for treating anxiety in children with ID using the CBT approach.

Methods

We searched PsycINFO for relevant studies from 1980 to 2014. Additional references were obtained through reviewing reference lists of relevant articles. Due to the few number of published articles found on the use of CBT in treating anxiety among children with ID (i.e., n = 2), the search was broadened to include publications that explored and/or discussed adaptations of CBT in treating anxiety among adults with ID. Studies focusing on individuals with Autism Spectrum Disorder were excluded due to qualitatively different nature of these populations in processing emotions. The search resulted in 10 articles in total. The articles were then reviewed to identify modifications to the CBT procedures that have been proposed and subsequently proved effective in treating individuals with ID for anxiety.

Results

Based on the current literature and years of clinical experiences of the current authors, several guidelines in adapting CBT in working with children with ID are proposed. These include significant involvement from parents, the addition of emotion identification as a component of treatment, an increased use of visual aids, the use of concrete activities in discussing abstract concepts, frequent review of concepts taught, and a heavier emphasis on the behavioural component of CBT. Examples of applying these general strategies in treatment sessions will be provided in the presentation.

Discussion/Conclusions

Whereas CBT is a well-established treatment for children and adolescents without ID, the clinical work and research on adapting CBT treatments for children with ID lags far behind. The current project represents a first-step towards establishing a manualized CBT treatment protocol for anxiety among children with ID. Empirical research based on the current recommendations is much needed to substantiate CBT as an effective alternative for treating anxiety in this population.

Barriers and Facilitators to Successful Transitioning of Adults With Developmental Disabilities From Inpatient Psychiatric Services to Community Settings

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Objectives

Transitioning from a hospital into a group home can sometimes be a difficult and lengthy process for adults with developmental disabilities (DD). To ensure that community placement is successful, several factors must be taken into consideration, such as environmental accommodations, availability of health and psychiatric services, or interdisciplinary communication. A handful of studies have considered the experience of hospital discharge from the patient and family perspective, but few studies have explored the ingredients that promote successful discharge from the viewpoint of hospital and community staff. The purpose of this study is to identify barriers and facilitators in these transitions, as seen through the view of hospital and community staff, through an in-depth review of 5 recent hospital discharges.

Methods

We employed a case series approach to gain an in-depth understanding of patient needs and discharge issues for 5 men discharged from a specialized psychiatric inpatient unit over the course of 1 year. Data sources included hospital charts, and interviews with hospital staff (n = 6) and community agency staff (n = 7), as well as surveys completed by staff from receiving agencies. Interview and survey questions focused on elements of the discharge process, follow-up care, and crisis experienced after discharge.

Results

Major themes from the interviews included the importance of communication between hospital and community, role clarity, presence of point persons at the hospital and community agencies, staff readiness and comfort with the client, and family involvement. Staff also stressed the significance of consistency in discharge planning, scheduled follow-ups, and availability of hospital support to the community.

Discussion/Conclusions

This poster will present key data obtained in the study that emphasizes strengths and weaknesses of the current transition model for individuals with DD. Moving forward, the findings of this project will highlight important issues and provide groundwork to improving the discharge and transition, building up staff capacity, and creating a cost-effective process for resource-intensive, complex clients.

The Societal Impact of an Exercise Program for Adults With Autism and Intellectual Disability: Interviews With Gym Bystanders

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Objectives

Peer-mediated interventions, including peer support in the classroom, peer buddy systems, as well as peer incidental teaching, are known to have a positive impact on several social and communication behaviours in individuals with autism spectrum disorder (ASD).[1] However, very little research to date has reviewed the impact of such inclusion among these peers or other community individuals (i.e., the "bystanders" of the intervention). Therefore, the purpose of this study was to examine the perspectives of the bystanders of an adapted physical exercise (APEX) program for adults with ASD and intellectual disability (ID), regarding their attitudes towards individuals with ASD-ID exercising within a typical gym environment. This research will provide information on how the inclusion of people with disabilities in a community-based exercise facility is perceived by other gym users.

Methods

The APEX program provides a 12-week whole-body exercise training program for individuals with ASD-ID. Over the 12 weeks, the investigators identified gym members (n = 6) and staff (n = 1) who had been present during several APEX program training sessions. The investigators approached those who were identified as being "present" to participate in an individual semi-structured interview. Prior to participating in an individualized, audio-recorded, semi-structured interview, all participants (3 males, 4 females, age range 19-49 years, all university students) read and signed an informed consent form. The interviews were transcribed verbatim and reviewed multiple times in order to establish broad, common themes based on similar participant answers to particular interview questions.

Results

Three broad categories were established: (1) the importance of inclusivity and exposure, (2) personal workout routines were unaffected, and (3) supportive of inclusive fitness facilities. Each theme is supported by multiple quotes ("meaning units") from a minimum of three participants.

Discussion/Conclusions

Analyses revealed that there is promising evidence to suggest that integration of individuals with disabilities into a community fitness setting have several worthwhile and positive benefits for the general gym user. Through this integration, we are fostering and creating a more understanding and accepting community for which all individuals with differences can thrive. We are also teaching our communities to become more comfortable with, open to, and understanding of individuals with disabilities. However, it is important to note some associated limitations. The small sample size comprised solely of students may not represent the views of the general population. Also, recruitment began as the APEX program was still in progress, making it possible that participants who were recruited may have been focusing on the APEX program in preparation for their individual interview. This introduces the possibility of social desirability bias. Despite these limitations, these findings suggest that further research is needed in order to determine more specifically how this integration is perceived by the general population.

References

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An Evaluation of Participatory Action Research

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Objectives

Research focused on persons with intellectual and developmental disabilities (IDD) has traditionally placed these individuals in the passive role of "participant." Participatory Action Research (PAR) is a research approach that helps persons with IDD contribute meaningfully to the research. PAR is a process in which the community under study participates actively with the researcher throughout the entire research, from initial design to final presentation of results, and seeks information to guide future actions. Furthermore, it provides a unique opportunity to involve the people most affected by the research in the research and to capitalize on their credibility and authenticity. The study's goals were to 1) evaluate the feasibility and utility of the PAR approach in IDD research, and 2) determine the degree of inclusiveness this approach offers persons with IDD.

Methods

The PAR approach was used in a project which investigated Person-Directed Planning as a means to build community capacity. It involved three planning teams working with four individuals with IDD. Through focus groups, the planning teams reflected on their success in building community capacity through PDP, and developed products to share their stories with other planning teams, and the public. Four meetings were held with each focus group. We monitored how PAR was implemented and whether it fostered participation among the collaborators with IDD and their planning teams. Through surveys and group discussions, we examined: (1) the time and percentage of contribution to the discussion by each team member, (2) the extent to which team members contributed to decisions made about the research and its outputs, (3) the benefits and challenges of using PAR in IDD research as perceived by team members.

Results

Analysis of the focus group discussions revealed that there was clear evidence of planning, acting, and thoughtful reflection through the focus group activities. Planning team members, contributed as much as the researchers. Survey data revealed that researchers and participants agreed that the "power" was shared equally between them and that it was easy to communicate with each other. Further analysis showed that the individuals with IDD were heavily involved in the discussion and planning of the project. However, as the task complexity increased and the support needs of the collaborator with IDD increased, the amount of time the individual with IDD contributed decreased.

Discussion/Conclusions

The research and planning teams were able to follow and implement a PAR approach successfully. Furthermore, PAR facilitated completion of the greater research project. The methods were successful at engaging persons with IDD as they actively contributed to the planning and conception of the team projects. Despite some challenges and limitations, the study was a positive experience for the research team and the project teams. This encourages further research to apply PAR principles in research with persons with IDD.

Participation, Self-Advocacy, and the Convention on the Rights of Persons With Disabilities for Transitional Aged Youth

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Objectives

The purpose of my study is to better understand if and how the fundamental right to participation (set forth in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) article 3) is being implemented for transitional age youth with intellectual disabilities in regards to employment (UNCRPD 27), education (UNCRPD 24), relationships (UNCRPD 23), and community involvement (UNCRPD 19). In this study, I will examine how the right to participate in life decisions, set forth by the UNCRPD, is being implemented by parents and developmental, mental health and educational services professionals for transitional age youth with intellectual disabilities as they leave high school. The proposed study is important as, to the best of my knowledge, there has yet to be a study that focuses on the participatory rights of transitional age youth with intellectual disabilities. The rights set forth by the UNCRPD attempt to protect the rights of persons with disabilities, however, the rights of persons with intellectual disabilities continue to be ignored and abused (Tarulli et al., 2004). Despite Article 3, the dreams and aspirations of transitional age youth are often silenced because of perceived barriers and limitations.

Methods

Semi-structured interviews will be conducted with five to ten professional informants recruited through the Niagara regional Committee on Transitional Aged Youth, and five to ten parents of transitional aged youth with intellectual disabilities. As this is a qualitative study, all results will be analyzed for themes based on the UNCRPD articles 3, 27, 24, 23 and 19.

Results

The results of this study are pending as we are very early in our study, however I hypothesize that the right to participate is not being fully implemented for transitional age youth with intellectual disabilities in the decisions affecting life after high school.

Discussion/Conclusions

This study will create an awareness of the needs and challenges faced by transitional aged youth with intellectual disabilities in the decision making process that will affect their futures, specifically raising awareness of education, employment, and community participation barriers. This awareness will provide a foundation for the future development of training materials in self-advocacy for transitional aged youth with intellectual disabilities. The data from this research will be used to create a game in my masters that will help transitional aged youth to learn about their choices after high school and to learn how to participate actively in the decisions affecting their future.

The Development and Use of a Frailty Index for Aging Adults With Intellectual and Developmental Disabilities

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Objectives

The population of persons with intellectual developmental disorders (IDD) is growing larger and older compared to previous generations. In general, they face higher risks for negative health outcomes and increased health care needs. This study assesses the ability of a frailty measure to predict time to admission to long-term care from home care, and to compare it to an existing measure of health instability currently used in Ontario. This study also compares the rates of long-term care assessments of adults with (IDD) to those without IDD. The identification of frail individuals could provide the opportunity for maintained independence and improved quality of life.

Methods

Individuals with IDD (aged 18-99 years) living in the community and receiving home care between 2007 and 2014 were included, identified through various Ontario health data sources (n = 4,510). To measure health instability, the Changes in Health, End Stage disease, Signs and Symptoms (CHESS) scale, embedded in the Residence Assessment Instrument-Home Care (RAI-HC) was used. To measure frailty, a frailty index that captures the accumulation of health deficits, adapted for the IDD population, was developed using well-established criteria. A modified Cox proportional hazards model will be used to find the association with time to admission to long-term care. A random sample of 20% of the population accessing home care without IDD will be used for comparing rates of long-term care assessments.

Results

Results are not yet available but preliminary analyses suggest that health instability is less common in home care recipients with IDD compared to those without but admission to long-term care is more common.

Discussion/Conclusions

It was anticipated that adults with IDD experience aging much earlier than the general population and are at increased risk for long-term care. The creation of a frailty measure specific for an IDD population has never been done in a Canadian health care setting. Early identification of individuals at risk for admission to LTC would benefit health policy planning and health care service allotment.

More Than Meets the Eye: Autistic Courtship Behaviours Explained by Theory of Mind

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Objectives

Many youth and young adults with autism are interested in having a romantic relationship (Byers et al., 2013). Success in this area is often challenged, however, by inappropriate courtship behaviours (Stokes et al., 2007). In this study, we investigated the roles of communication and Theory of Mind (ToM) as possible mediators explaining the association between autism and inappropriate courtship. A non-clinical sample varying in number of autistic symptoms was used for this purpose.

Methods

A total of 124 university students (Mage = 19.7 years, 85% female) completed an online survey consisting of four measures including the Autism Quotient (AQ) of Baron-Cohen et al. (2001a) and the Courtship Behaviour Scale (CBS) of Stokes et al. (2007). Two measures of ToM were also completed. The first was the Eyes Test-Revised (Baron-Cohen et al., 2001b) which assesses the ability to infer complex mental states from the eye expressions of others. The second was a self-report measure of the tendency to over-perceive the behaviour of others as flirtatious. This measure was created for the present study.

Results

First, the zero-order correlation between the measure of autistic symptoms (AQ) and inappropriate courtship (CBS) was evaluated and found not statistically significant. However, the communication subscale score of the AQ did predict inappropriate courtship ($r = .22$, $p < .05$). PROCESS mediation analyses (Hayes, 2013) subsequently suggested that this effect was indirect and complex, involving both aspects of ToM. Difficulties in communication predicted poorer ToM as assessed by the Eyes Test, and poorer ToM was associated with increased inappropriate courtship. Serial mediation analysis also revealed a second pathway, in which poorer ToM was associated with increased perception of others' flirtations, which was then associated with increased inappropriate courtship.

Discussion/Conclusions

The results did not suggest a direct link between total autistic symptoms and inappropriate courtship behaviours but did support a link between autistic communication symptoms and inappropriate courtship behaviours. Two paths were revealed for the latter relationship. One path was mediated by difficulties inferring mental states from eye expressions. The second path involved two mediators. Difficulties inferring mental states were associated with an assumption that others are flirting with them, and the latter factor was associated with a greater variety of self-reported inappropriate courtship behaviours. Our findings highlight the role played by a delayed theory of mind in the courtship challenges of individuals with autism. Identifying factors that make forming relationships difficult in this population is important so that practitioners can address them and help interested individuals with autism fulfil their relational potential. The development of a better model of the factors associated with inappropriate courtship behaviours may also assist forensic psychologists asked to assess and possibly exculpate some individuals with developmental disabilities who are accused of "stalking." Results should be interpreted with caution given the limited psychometric validation of one of the measures (the measure of others' flirtatious behaviours) and use of a non-clinical sample. To our knowledge, this is the first study to examine factors that may account for the association between autistic symptoms and inappropriate courtship behaviours.

Presence With a Purpose: Attitudes of Patients With Developmental Disability Towards Health Care Students

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Objectives

Medical and nursing students benefit from early clinical encounters to build professional competencies, particularly communication skills. At the same time, there is a necessary emphasis on appropriate consent and autonomy in their own care. While most individuals in the general population do not mind having a student either present or otherwise involved with their clinical encounters, there are occasions when personal preference and health care education conflict. Many studies have evaluated patient attitudes towards students across a variety of specialties. To our knowledge, no study has specifically evaluated the opinions of individuals with developmental disabilities (DD). Our objectives in this study is to identify the attitudes, preferences, and comfort level of individuals with DD towards the presence and involvement of medical and nursing students during clinical encounters.

Methods

Individuals with a DD in the Hamilton-Niagara region were invited to participate in this study. Developmental Service Providers were involved with invitations to participants. Participants were provided with focus group questions in advance and encouraged to bring communication aids and/or care providers. Data was collected from the focus group discussions and individual written responses. Two independent reviewers analyzed the data and compared results for emerging themes.

Results

Twenty-two individuals participated in this study, most of whom had previous experiences with health care students. There was a wide range of attitudes expressed. Some were positively disposed towards medical and nursing students and were happy to have contributed to someone's learning. There was a perception of better care and improved communication with the health care team as additional benefits. Others were indifferent to students and the role they play in a clinical setting. The final group were strongly opposed to the presence of care students during clinical encounters due to significant concerns regarding confidentiality. Improved introductions and confidentiality statements, as well as presence of both the doctor and student in the room, helped relieve such concerns, though not completely. Furthermore, individuals expressed confusion over the role and purpose of students' presence, as well as uneasiness with deviation from the norm of seeing a practicing doctor and nurse.

Discussion/Conclusions

A variety of attitudes, preferences, and comfort level towards the participation of health care students is described. The themes that emerged from focus groups were developed into recommendations for engaging persons with DD in clinician training. The results of this study should serve to influence health care training to improve the professional competencies of medical and nursing students and quality of care people with DD receive.

How to Make it Work: An In-Depth Case Study of Inclusion in a Community Figure Skating Club

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Objectives

The purpose of this research is to develop a framework that community sport organizations will be able to use to allow for the full integration of children with disabilities into the sport community.

Methods

The approach used for this study is an in-depth case study of a community figure skating club, and is one of few clubs housed under Skate Ontario that specifies “special needs accommodation” in their description. The methods used are semi-structured interviews with coaches, parents, and children (both with and without a special need accommodation). In addition to interviews, the researcher will lead a focus group with the Board of Directors of the figure skating club. The final method to be used for this study will be document analysis including records from the local club as well as Skate Ontario.

Results

Preliminary analysis suggests that simply meeting standards does not necessarily guarantee an environment that is authentically inclusive. Coaching pedagogies that utilize task breakdown seem to be indicators contributing to more individualized programming and has more authentic inclusion. The current literature trends are not going in the direction of task breakdown within the sport organization and therefore the study should yield useful and interesting results.

Discussion/Conclusions

This research aids in the progression of both the Sport Management literature as well as the field of adaptive physical activity. Currently, there is very minimal works that address the issue of inclusion at the community sport level from the organization’s view.

Measuring The Stress of Parents of Children With ASD in Modern Times: Comparing Phone and Email Communication

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Objectives

Although increased support has been found to reduce the stress experienced by families of children with an autism spectrum disorder (ASD) (e.g., Weiss et al., 2013) parent ratings indicate low perceived support from professional organizations (Hall & Graff, 2011). The ability of an organization to determine the stress of families that contact them is an important first step to responding according to the family's needs. Autism Ontario (AO) is a charitable organization that provides a province-wide and leading source of information and referral on ASD in Ontario. Between 2007 and 2009, 63% of contact to Family Support Coordinators (FSCs) of AO occurred through email. However, it is more difficult to express or interpret emotions over email because of the absence of verbal and body language cues more typically present in phone or in-person communication (Byron, 2008; Ekman et al., 2004) and, as a result, there is a greater risk for FSCs to misinterpret family stress over email. Since 2013, AO has been collecting data on the stress of families who contact the organization either over the phone or via email. This project presents a comparison of the results of parent stress before and after contact with AO FSCs through either phone or email communication.

Methods

Phone stress was collected on an ongoing basis. FSCs keep a record of all phone calls received and, when communication involves parents requesting information and assistance, FSCs reported parent stress before and after phone communication into an online database. Email stress was collected at four equally-spaced time points throughout the year. Each of the time points served as a trigger for FSCs to forward the email addresses of families who had contacted them in the preceding week to the AO research team. The researchers then sent these families a brief online survey that inquired about their overall experiences with email communication with AO that past week, including reporting on how much stress they had been experiencing prior to contacting FSCs and how much stress they experienced after the email exchange.

Results

Over a 9-month period, phone stress data was collected from 329 families and email stress data from 49 families. A large number of families communicating with FSCs over email considered themselves "very stressed" (35%) prior to contacting FSCs. This is in contrast with only 5% of families who contacted FSCs over the phone, the majority of whom rated themselves as being either "moderately stressed" (35%) or "a little stressed" (34%) prior to contact with FSCs. 53% of families who initiated contact over email reported a reduction in stress following their correspondence with FSCs while another 41% reported no change. Similarly, 48% of families who initiated contact over the phone reported a reduction in stress, while the remaining 52% of families reported no change.

Discussion/Conclusions

The findings suggest that, despite the increased possibility of emotional detachment in email correspondence, it is still possible for organizations to measure and help alleviate the stress of families of children with ASD through email communication

Comparing Predictors of Quality of Life in Families With or Without Children With Severe Developmental Disabilities

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Objectives

Research suggests that both children with developmental disabilities (DD) and their parents face challenges that may result in reduced quality of life. For example, parents of children with DD report that they have difficulty identifying friends for their children (Guralnick et al., 2006) even though they believe that having friendships will positively contribute to their child's quality of life (Overton & Rausch, 2002). Similarly, parents of children with DD also report difficulty maintaining their own social relationships due to the increased demands on time that are associated with caring for their child with DD (Helitzer, Cunningham, Sabo, VanLeit, & Crowe, 2002). The social outcomes for families of children with DD are not homogeneous and it is possible that factors such as the child's specific diagnosis (Sigman & Ruskin, 1999), level of communicative impairment, behaviour problems (Renty & Roeyers, 2006), and school setting (Carter et al., 2014) may be predictive of the number of friendships and quality of life of the child as well as the subjective well-being and quality of life of the parent. The goal of the present study was to determine what factors are predictive of quality of life in children with severe DD and their parents, when compared to families of typically developing (TD) children.

Methods

This study is part of the larger GO4KIDDS project looking at the experiences of children with severe DD in Canada. Parents of 454 children with severe DD (age M = 11.18, 70% male) and 210 TD children (age M = 10.65, 69% male) completed surveys on the general health, well-being and social inclusion of both the children and the parents.

Results

Preliminary results suggest that 66% (n = 236) of parents of children with severe DD reported that their own social lives had suffered as a result of caring for their child. Similarly, 28% (n = 119) of children with severe DD were reported as having no friends (non-relatives) and 71% (n = 291) of parents of children with severe DD, reported that their child's friendships were of either "poor" or "very poor" quality. Parent reports indicated that 62% (n = 262) of children with severe DD were judged to be "quite happy" or "very happy" but parent reports indicated that only 29% (n = 121) were believed to be reaching their full potential. Ongoing analysis will focus on identifying predictive relationships between child and parent characteristics (e.g., child's specific diagnosis, parent's physical health) and factors related to quality of life (e.g., number of friends, happiness).

Discussion/Conclusions

Our results indicate that, although children with severe DD and their families face increased challenges to social well-being and quality of life when compared to their TD peers, results are variable within this group. This highlights the need to look at resilience factors and individual differences that are predictive of more positive outcomes for families (Gardiner & Larocci, 2012). Such information can be used to guide family interventions and inform the provision of services that can best address the needs of families of children with severe DD.

Life Events and Psychopathology in Adolescents and Adults With Autism Spectrum Disorders

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Objectives

There is growing research to suggest that individuals with Autism Spectrum Disorders (ASD) are more likely to suffer from comorbid psychiatric diagnoses than the general population (Leyfer et al., 2006). However, very little is known about how particular psychiatric disorders are related to the experience of life events within this population. This is important given that both life events and psychiatric disorders contribute to the experience of crisis within this population. Life events experienced by those with ASD can impact interpersonal and routine-based distress but we do not know much about which life events are most likely to occur in this population. The current study examines the prevalence and types of life events that adolescents and adults with ASD experience and will explore the relationship between life events and mental health issues.

Methods

Three hundred and ninety-six families participated in a longitudinal study on the health service use of their adolescent or adult children with ASD. Of those, 283 families provided information on life events at baseline and 3 follow-up periods. Similar to Milovanov et al. (2013), items from the significant life events scale were collapsed into 18 categories. The descriptions provided by parents under the "other" category were re-coded into the 18 categories where possible.

Results

At baseline, 58.0% of the sample reported experiencing one or more life events over the past two months, the most frequently reported life events being mistreatment (22.3%), serious illness of a close relative, caregiver or friend (11.7%), and a change in primary staff/worker (11.7%). Individuals with a current psychiatric diagnosis were more likely to have had at least one significant life event in that 2-month period (67.2%), χ^2 (1, N = 283) = 8.18, p = .004.

Discussion/Conclusions

We are currently examining cumulative life events over a 6-month period, and the association between such life events and psychiatric issues. From baseline data alone, we see that life events are common in this population, and that the occurrence of life events is associated with psychiatric disorder. It is important to support individuals with ASD when life events occur given the impact that life events may have on their emotional well-being.

Supported Entrepreneurship: The Social Return on Investment

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Objectives

As part of the Social Business and Marginalized Social Groups Community University Research Alliance based at the university of Toronto, Common Ground Co-operative and Brock University researchers have been examining the impacts of Common Ground Co-operative's approach to supported entrepreneurship for persons with developmental disabilities. The present study focused on calculating the organization's social return on investment (SROI) (Nicholls et al., 2009). Common Ground Co-operative provides administrative, educational and job coach support to 62 persons with developmental disabilities in five social enterprises all located in Toronto. These 62 people are non-share capital partners in these enterprises.

Methods

This study built on themes from earlier studies (Bishop, 2013; Owen, Readhead, Bishop, Hope, & Campbell, in press). The present study added four individual interviews and a focus group with five social enterprise partners. In addition, phone interviews were conducted with five parents of partners. The focus group and interviews were designed to obtain descriptions of specific outcomes of participation Common Ground Co-operative training and job support for the partners and their families. Accounting calculations of SROI included comparison of the organization's services to proxies from other job training and employment support programs. Additional SROI calculations were based on organizational efficiencies identified in an earlier study (Bishop, 2013) and calculated by analysis of five years of financial statements.

Results

Interview and focus group results were analyzed in the context of the impact of Common Ground Co-operative on quality of life of persons with developmental disabilities (Schalock & Verdugo, 2012). Partners and family members described changes in social enterprise partners' independence, social participation and well-being. In addition, family participants described reduction in their stress when their family member was accepted into Common Ground Co-operative's programs. Proxy comparisons were used to calculate the value of Common Ground Co-operative's training and employment support. The Common Ground Co-operative Foundations Program training was compared with College Community Integration Through Co-operative Education (CICE) programs and the organization's ongoing employment support was compared with a community organization that provides day program and community participation supports for persons with developmental disabilities. The added value of volunteers, low staff sick day claims and low staff turnover (both related to organizational culture), and minor carbon savings were also factored into the SROI calculations. SROI is not an exact accounting calculation however, using two realistic approaches to Common Ground Co-operative's funding and examining the savings and added value calculated through the SROI process, the range in annual return was 28%–51%.

Discussion/Conclusions

The SROI narrative and accounting descriptions of the program content and outcomes provide a compelling picture of the return that funders can expect from their investment in Common Ground Co-operative. In a climate of constrained government funding and increasing pressure on corporate and private donors, SROI provides a way for social service organizations to clarify the contributions they make to the individuals they serve directly and to the larger society. The proposed presentation will elaborate on the results and implications of SROI for service advocates and administrators.

Support Groups for Parents of Adults With Developmental Disabilities: Barriers to Attendance

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Objectives

Parents of adult children with developmental disabilities often experience high levels of stress and poor psychological and physical wellbeing. Despite this, very few interventions exist to support parents. This is particularly concerning given our knowledge that parents who are highly stressed are less able to support their child, and experience poorer mental health. To address this issue, we offered parents a free support group aimed at reducing stress, depression, and anxiety, while increasing empowerment, psychological wellbeing, and acceptance. Although these sessions were free and respite care was provided, parents faced a number of barriers attending the groups. The following study aimed to discover which specific barriers to attending parent groups were encountered by parents with adult children with developmental disabilities.

Methods

Flyers advertising the Parent Support Project were circulated to parents of adults with a developmental disability through Developmental Services Ontario, Toronto region (DSO). Parents interested in the project, contacted the research team to register. Not all parents who contacted the research team were able to participate. Of those that participated, not all parents remained in the group for the full 7 weeks. Barriers to attendance were explored in 2 ways: (1) via parents who contacted us, but were unable to attend; and (2) via parents who registered and attended at least one session.

Results

In total, 96 parents expressed an interest in participating in the parent groups. Of these parents, almost half (49.0%) were unable to attend the groups after expressing initial interest. The most commonly reported barrier to attendance was timing. Over half of parents could not attend the group at that time because of work, school or other parenting responsibilities. Nearly 1 in 5 parents could not attend because of transportation issues, with the setting being either too far, or not being able to use public transportation. Other reasons for not participating included child issues (either child care, or child health), or parent issues including parent health or language barriers. Of the 49 parents who were able to attend the groups, the majority (85.7%) attended the groups regularly (attended at least 4 of the 7 sessions), with only 14.3% either withdrawing (4) or attending fewer than 3 sessions (3). The most commonly cited barriers to regular attendance included: (1) child issues (40% – includes childcare, child health problems), (2) parent issues (40% – includes health problems, language), and (3) transportation.

Discussion/Conclusions

Results suggest there are a number of different barriers parents of adults with developmental disabilities encounter to attending parent support groups. These barriers should be considered when developing and organizing future groups for parents to help make them more accessible.

Service Delivery to Individuals Affected by Autism Spectrum Disorders and Their Families

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Objectives

An individual with ASD requires access to services that help with daily life, educational goals, employment and other lifestyle needs. The importance of services during the transition into and throughout adulthood has shown significance and can have an effect on the ability to obtain employment and support. This study analyzes the accessibility of services and support for adolescents transitioning into adulthood with Autism Spectrum Disorder. It also outlines the barriers to overcome in order to utilize services to benefit both the individual as well as their families.

Methods

Qualitative interviews were conducted by experts in the Autism field and obtained information from young adolescent and adult individuals diagnosed with Autism Spectrum Disorder, their siblings and family members. The interviews were completed in a preferred place by the participant. The topic of service delivery was covered by both the participant and their caregivers. Five families were interviewed (caregiver N = 7; individuals diagnosed with ASD = 5; siblings = 4). Interviews were audio-taped and transcribed and have been coded for themes.

Results

The response from the interviews showed that there were barriers in order to access services. In a specific situation, there was a hard time obtaining services from the school the child attended, it was not until the mother intervened and outlined what should be done that any progression was made. The difficulty in finding available services is only half the battle, being able to afford these services is a separate issue. The data shows that service delivery for Individuals with Autism Spectrum Disorder is inaccessible at times and has many barriers. However, even though it is hard to access, services can be extremely helpful and beneficial.

Discussion/Conclusions

Resilience in relation to service delivery has a significant connection. The individual who uses the available services will seek help from their family to access them. These services can be provided by local groups, government sectors and separate companies. Funding for use can be distributed by the government to families based on their situation. Families rely on these services for normal day-to-day life experiences or for more stressful situations. All of these can be helpful to both the individual and the family psychologically and socially. The difficulty of achieving success is not reflected in the ability of the individual but in the services that fail to deliver. As indicated by the above research, individuals with ASD and their families can benefit from multiple service agencies in order to receive an adequate amount of needed support and therefore require adequate funding.

From Adjustment to Adaptation: Families Raising Adopted Children With FASD in Ontario

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Introduction

Existing Fetal Alcohol Spectrum Disorder (FASD) research suggests that the majority of individuals raising children with FASD are adoptive or foster parents (Rowbottom, Merali, & Pei, 2010), but limited research has been conducted on the experience of non-biological families raising children with FASD in Canada (Watson, Coons, & Hayes, 2013). Many adopted individuals with FASD are diagnosed post-adoption (Williams, Dubovsky, & Merritt, 2011), but documentation of prenatal alcohol exposure is extremely difficult to obtain, thus confirming a diagnosis of FASD can be challenging. Ontarian resources are available for parents of adopted children with FASD, but little is known about their actual needs and available resources.

Methods

Thirty adoptive parents with at least one child with FASD were recruited through FASD support groups across Ontario. Using a mixed-methods approach, informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994), parents completed five quantitative questionnaires and a semi-structured interview. The questionnaire battery included the Parenting Stress Index (Short Form), Family Crisis Oriented Personal Scales, Child Behavior Checklist, Questionnaire on Resources and Stress (Friedrich's Short Form), and the Hope Scale. The interviews were analyzed using Interpretative Phenomenological Analysis (IPA) to gain an understanding of their lived experiences (Lyons & Coyle, 2010). Using a convergent parallel mixed methods design, the quantitative questionnaire data and qualitative interview themes were compared and contrasted (Teddlie & Tashakkori, 2009). Differences in family adaptation factors (i.e., capabilities and resources) were examined.

Results

Data analysis is in progress and full results will be available for this poster, but preliminary analysis of interviews reveals both challenges and rewards for families raising adoptive children with FASD. Parents discussed barriers to adaptation including a lack of information about the adoption, a lack of resources available when the adopted children reach adulthood, and a lack of understanding held by some formal supports, but parents also discussed strategies they found helpful including using humour as a coping mechanism, the use of support groups, and picking their battles. To triangulate the qualitative data, each theme will be further substantiated through highly endorsed items throughout the battery of questionnaires (e.g., how parents responded to the question, "When we face problems or difficulties in our family we respond by seeking encouragement and support from friends" on the F-Copes).

Discussion/Conclusions

The present study will provide a rich, descriptive picture of the experience of raising an adopted child with FASD in Ontario. The results of this study will be used to inform Ontarian adoption agencies and general FASD formal services of the unmet needs of families of adopted children with FASD, as well as which services they consider to be most helpful.

Support Received by Women With Intellectual and Developmental Disabilities During Pregnancy and Childbirth: A Case Study

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Objectives

There is a growing number of women with intellectual and developmental disabilities (IDD) in the maternity population. In Ontario, there were 20.3 live births for every 1,000 women with IDD in 2009. Individuals with IDD generally have impoverished social networks, with most experiencing low to moderate levels of social support. However, very few studies have described the social networks that exist to guide women with IDD during pregnancy and childbirth. Indeed, women with IDD are currently a largely invisible maternity population. Our objective is to describe the structure and perceived quality of social support experienced by women with IDD throughout pregnancy and childbirth.

Methods

We will present two in-depth case-studies selected from a larger grounded theory study which aims to develop a conceptual framework quantifying and qualifying the social support experienced by women with IDD during the perinatal period. Using information-oriented sampling, the cases providing maximal informative content will be selected from the larger sample of participating adult women (18+ years old) with IDD (as confirmed by developmental services agencies) who (a) have given birth in the last five years, irrespective of legal guardian status, and (b) have sufficient cognitive and verbal ability to answer questions about pregnancy and childbirth in an interview setting. Participants will be recruited from developmental services agencies based on service provider knowledge of women meeting the above eligibility criteria. Accessible information packages about the study will be sent to potential participants by association members. Following screening and basic demographic information ascertained through a telephone interview, detailed qualitative data will be collected through one-on-one semi-structured interviews based on a modified version of the Social Support Self Report (SSSR). For the purposes of our research, prompts were added in follow-up to the SSSR questions to elicit detailed qualitative information specific to pregnancy and childbirth. Interviews will be recorded and transcribed verbatim for analysis; content analysis will be carried out by two researchers. For each of the selected cases, we will present emerging themes, along with illustrative quotes, related to the structure and perceived quality of social support received during pregnancy and childbirth.

Results

We are currently recruiting participants. Results are forthcoming.

Discussion/Conclusions

These cases will offer rich, narrative detail on the sources of formal and informal social supports experienced by women with IDD during pregnancy and childbirth. A limitation to consider when interpreting the data is that our sample will only include women who have sufficient cognitive and verbal ability to remember and relay retrospective accounts of their maternity experience. This population is not homogenous therefore, information will not necessarily reflect the maternity experience of all women with IDD. Nevertheless, this depth of insight has not previously been available on this topic. Such information will be useful to generate hypotheses upon which future research can build. A greater understanding of the social supports available to women with IDD during pregnancy and childbirth will inform development and improvement of services that support women with IDD.

From Research Into Practice: A Review of the Literature and Examination of Clinical Cases Series Pertaining to the Differentiation of Acquired Brain Injury and Learning Disabilities

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Objectives

Paediatric acquired brain injury (ABI) is commonly associated with several neurocognitive sequelae that impede children's learning, behavioural and social functioning and, otherwise, success inside and outside of the classroom environment. Despite increasing awareness about the effects of brain injury, misdiagnoses of the neurocognitive impairments that impede learning functioning as learning disorders (LD) is a common clinical challenge. This creates difficulties for students who require assistance, as oftentimes they are mislabelled, are placed in a program not suited to their needs, or do not receive assistance. These difficulties are further exacerbated by the fact that only two Canadian provinces/territories presently acknowledge ABI as an exceptionality within the educational system. As a result, even when students with ABI are appropriately diagnosed clinically, the neurocognitive sequelae that impairs their learning most commonly also results in the formulation of individual educational plans for LDs. The current project informs clinicians, teachers, and front-line workers regarding the differentiation between learning disorders and ABI, provides remediation and compensatory strategies that have been shown to be clinically efficacious for each disorder, and highlights the ramifications that misdiagnoses can have on students emotionally, socially, and behaviourally.

Methods

A systematic review of the literature was performed examining literature pertaining to the respective clinical presentations associated with LDs and ABI, the neuropsychological instruments pertinent to the differentiation between these two disorders, as well as the strategies that have been illustrated to be clinically efficacious for each type of impairment. Further, a clinical case series involving three clients who had sustained moderate to severe ABIs, but had been previously misdiagnosed with LDs was investigated.

Results

It is well acknowledged that ABI is highly heterogeneous in the respective cognitive, behavioural, and social impairments that ensued following injury; relative to LDs, the neuropsychological profile reflects widespread limitations with skill sets that are particularly vulnerable to injury depending on the type of ABI (e.g., near-drowning, traumatic brain injury, etc.). Furthermore, while little research has been conducted to contrast these two populations, it is clear that the etiology, onset, and diffusivity of impairment are cardinal features of ABI that impede the successful strategies typically efficacious for those with LDs. Given that LDs are predominately genetic or congenital, these impairments in learning have persisted throughout their development; thus, children have developed a number of compensatory strategies themselves to aid their learning. Moreover, LDs are characterized by reasonable insight and situational specific frustration. Conversely, ABI is associated with abrupt onset, with little opportunity for self-derived compensatory strategies, and is not situation specific. Those with ABI tend to have poorer insight; and their frustration/emotional outbursts may be due to in part to compromised self-regulatory/executive function skills.

Discussion/Conclusions

The differentiation between LDs and ABI is a clinically meaningful distinction that requires maintenance throughout the educational system. Distinct cognitive profiles and clinically efficacious strategies have been identified for both disorders, but the success of these strategies is highly dependent on proper identification. Misdiagnoses or categorizations are associated with poorer outcomes with respect to cognitive, emotional, social, and behavioural functioning.

Sexual Offender's Perceptions on Early Life Experiences: Role, Gender and Forms of Parental Attachment

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Background

Sexual offending is considered to be one of society's most deviant and horrific behaviours. However little is known about early life experiences of parental attachment, which may have an effect on the future development of sexually deviant behaviours. Specifically, whether there are differences in gender, parental role, and forms of attachment in early childhood between mother, father and the child. Using a feminist approach through grounded theory, this qualitative study will examine perceived attachment styles of those sex offenders who are currently residing in a medium security treatment facility, using a semi-structured interview. The aim is to better understand the risk factors of sex offenders so that improved clinical strategies can be implemented.

Purpose

To examine perceived early life experiences, identifying family/social variables in an effort to determine possible risk factors leading to dysfunctional interpersonal relationships or sexual deviance later in life.

Part one. Attachment theory was used as a framework to explain offender's perceptions of interpersonal relationships (mother vs. father).

Part two. The study was analyzed through a feminist lens, to examine gender and power relations (of mother and father), and how this contributes to the offender's social constructions of gender, norms, and values with respect to gender differences.

Methodology

Through a feminist lens, this research compared gender roles/power relations, observed by the offender's with respect to their mother and father during early childhood years. Perceived bonding styles between parent-child were also compared by genders.

Methods

This study was conducted using a semi-structured interview method, through grounded theory. Two male participants with a dual-diagnosis, and a history of engaging in sexually offensive behaviours (with a prior conviction), were randomly selected for interview. Both participants were Caucasian between the ages of 21 and 24 years old, residing in a medium-security treatment facility within the developmental disability sector.

Results

Part one. Attachment styles:

- Secure attachment-mother-child (both participants)
- Insecure-avoidant attachment-father-child (both participants)

Part two. Gender roles/power dynamics (mother/father):

- Drawing on liberal and feminist theories as a framework; exposed family or social variables associated with gender roles, identities, and constructions of power relations, which may pose a significant contribution to their subsequent deviant offense patterns.

Please note: The research is in progress, and the above results are current results to date. The estimated completion date of this project is March 30, 2015.

Discussion/Conclusions

The presentation will elaborate on these preliminary results, involving the discussion of grounded theory codes, and specific results related to how early life experiences, and social factors may result in risk factors associated with deviant behaviours in adulthood.

The Social Inclusion of a Child With a Severe Developmental Disability in School and the Community

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Objectives

Children with Developmental Disabilities (DD) are at higher risk of being socially excluded (Solish, Perry, & Minnes, 2010) and can experience low rates of social inclusion, even when they are in integrated settings (Cooney, Jahoda, Gumley & Knott, 2006). Overall, there has been very little research surrounding the social inclusion of children with Severe DD. The Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) Canadian team project, explores the health, wellbeing and social inclusion of school aged children with Severe DD. The GO4KIDDS Social Inclusion study has demonstrated that, in community settings child factors played a large role in children's social inclusion. Children in integrated or mixed settings had higher ratings of social inclusion than children in segregated settings, and more social inclusion occurred when the activities were structured (Carvalho, Bebko, & Perry, 2014). In this poser, we present a case study in order to gain an in depth look at the social inclusion of a child with a Severe DD.

Methods

"Jack" is an 8-year-old boy with ASD. A case study of his social inclusion in school and the community is presented. Data were collected from multiple sources including interviews with teachers, community leaders, and parents. Trained observers completed direct observations of social interactions in the school and community, providing information regarding the amount of time Jack spent interacting with others. Observers also completed ratings regarding how socially included they believed he was in each setting.

Results

Jack is in a mainstream, integrated class, and attends a day camp. An interview with his parents gave a positive picture of his inclusion in both school and the community day camp. Jack's teachers also provided a positive description of his social inclusion in the school setting. In contrast, his community leaders reported he had more difficulty being included socially with the other children. Jack engaged in a range of types of play during the observations, including being engaged with adults, proximity play (playing near other children), onlooker (watched other children play), and joint engagement (actively playing with other children). Ratings of Jack's overall social inclusion ranged from completely included to not at all/somewhat included.

Discussion/Conclusions

A combination of child factors and environmental factors appear to have contributed to Jack's different levels of social inclusion in the school and community. By examining these different child and environmental factors, we can better understand what helps and hinders the social inclusion process for Jack, and children like him, so that specific strategies can be developed to enhance children's social inclusion, regardless of their disability.

Comprehensive Health Assessments for Adults With Intellectual Disability (ID) in Manitoba

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Objectives

Researchers, practitioners, and decision makers are working together to determine the feasibility of implementing the Comprehensive Health Assessment Program (CHAP) for adults with ID in Manitoba. The CHAP was designed to help minimize the barriers to access primary health care for persons with ID. Research from Canada and abroad shows that significant health disparities exist between persons with and without ID. Despite poorer health and higher health-care needs, prior research shows that persons with ID experience more difficulty accessing proper health care than the general population. Persons with ID also reportedly have fewer opportunities to engage in health-promoting activities than the general population. As a result, preventable mortalities and comorbidities are more common among persons with ID than those without these conditions or than the general population. Results of the studies conducted in other developed countries show that health checks and Comprehensive Health Assessments can overcome some of the barriers to access proper health care for persons with ID.

Methods

To address the stated research objectives, we have conducted focus groups and individual interviews with GPs, Nurse Practitioners, formal and informal caregivers of persons with ID. An Interpretive Description design was used for this qualitative study (Thorne, 2008). Interpretive Description is a qualitative methodology grounded in the constructivist paradigm with an aim of generating knowledge useful for the clinical context of applied health disciplines (Hunt, 2009; Thorne, 2008). Qualitative methods Purposive sampling of physicians, nurse practitioners, direct support workers and families who support people with ID in Manitoba were recruited. Data collection was through semi-structured individual interviews and two focus groups. In total, we conducted 24 semi-structured interviews with caregivers and primary care providers. The caregivers consisted of both support workers (n = 13), and family members (n = 6). The primary care providers included general practitioners (GPs) (n = 2), and nurse practitioners (NPs) (n = 3). A total of 18 individuals participated in the focus groups. This sample size was considered sufficient to elicit understandings from important stakeholders in the topic of interest (Thorne, 2008).

Results

Four main themes were identified from the data. Benefits of implementing the CHAP were identified by every group. Some Barriers were identified, with the majority of them being discussed by the primary health care providers (GPs and NPs). Facilitators for the implementation of the CHAP however were also identified. Some needs were identified that would assist in successful implementation of the CHAP.

Discussion/Conclusions

Overall, in this study we found an overwhelming positive support for implementing CHAP in Manitoba. To overcome the barriers reported in the study, several steps have to be taken including development of training modules for health care professionals, paid support staff and unpaid caregivers; financial incentives for health care professionals and change in regulations to facilitate the implementation of the CHAP in Manitoba. Future studies should evaluate not only the short-term but also the long-term effectiveness of the CHAP for improving health, well-being and continuity of care in people with intellectual disabilities in Manitoba.

An Examination of the Specialized Support Within the Justice System for Accused With Fetal Alcohol Spectrum Disorder

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Objectives

There is a growing body of literature that examines the experiences of those with intellectual disabilities involved in the justice system as accused and the challenges they sometimes encounter when involved in the CJS. Current literature has found that individuals with the Fetal Alcohol Spectrum Disorder (FASD) sometimes experience challenges within the justice system, such as difficulties understanding abstract legal concepts as well as communicating with various justice professionals. Although the UN Convention on the Rights of Persons with Disabilities (2006) has created a legislative framework that provides a layout for equity within the justice system for individuals with disabilities as accused, victims and witnesses, there is relatively minimal research that examines the structural constraints of the justice system in effectively supporting accused with the specific diagnosis of FASD. This study examines the current supports and accommodations available in Ontario for persons with FASD when involved with the CJS. In addition, there is a focus on suggestions by key players within the justice system and social service agencies about ways to most effectively address the needs of individuals with FASD within the justice system.

Methods

In-depth semi-structured interviews will be conducted with approximately 30–40 support workers and justice professionals who work with persons with FASD. More specifically, between 15–20 participants will be professionals who work directly with individuals with FASD such as service support workers or administrators within agencies who support persons with developmental disabilities. The remaining 15–20 participants will be justice professionals who interact with individuals with FASD in a legal setting such as lawyers, police officers and diversion workers. Data will be collected within Ontario jurisdictions.

Results

Data is currently being collected within Ontario jurisdictions. Although the results of this study are pending, it is expected that there are limits to the traditional, legal accommodations used to support individuals with FASD in accessing justice at the various stages of the CJS, calling for more specialized supports to assist individuals with FASD who have specific needs.

Discussion/Conclusions

This research will help to inform academic and community-based organizations in assisting accused with FASD in navigating their way through the justice system with more ease, resulting in more equitable experiences.

Examining the Social Participation of Children With Intellectual Disabilities and Autism Spectrum Disorder in Relation to Peers

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Objectives

Participation in social and physical activities promotes physical, emotional, and social well being for children with or without disabilities (e.g., Geisthardt et al., 2002). However, despite the benefits, individuals with disabilities are often excluded from taking part in social activities (Bigby, 2012). Lack of opportunities to participate in activities may prevent exploration of various areas of development (King et al., 2003). Most of the research on activity participation has focused primarily on higher functioning children with disabilities. However, children with severe Developmental Disabilities are often excluded from this type of research because of their complexities and level of functioning. Therefore, the purpose of this study was to report and compare the social participation of children with Intellectual Disabilities (ID) and Autism Spectrum Disorder (ASD) in relation to a Typically Developing (TD) sample.

Methods

The GO4KIDDS project explores the health, well being, and social inclusion of Canadian school-aged children (4 to 19 years) with severe ID and ASD. A total of 186 parents of children with ID and 232 of those with ASD completed the Basic Survey. In addition, 210 parents of TD children completed the TD Survey. The surveys include a brief version of The Activities Questionnaire (Solish et al., 2010), which examines the frequency of participation of six types of activities. In addition, there are three questions regarding the child's number of friends, type of friends, and quality of these friendships.

Results

One-way ANOVAs revealed that the TD group participated in significantly more social activities than the ID and ASD groups. In addition, post hoc analyses revealed that the TD group participated more often in each of the six types of activities than the ID and ASD group. For some social and recreational activities, the ASD group participated significantly less often than the ID group. Ninety-nine percent of the TD group have friends, whereas, 82% of those with ID and 64% of those with ASD have friend(s) ($\chi^2 = 89.45$, $p < .001$). In addition, a greater number of children in the ID group had one or more friends than those in the ASD group ($\chi^2 = 17.46$, $p < .001$). The majority of the TD group have average to excellent quality of friendship, while the majority of the ID and ASD group have very poor to average quality of friendship ($\chi^2 = 216.73$, $p < .001$).

Discussion/Conclusions

Children with ID and ASD in this study were reported to participate in fewer social activities than their TD peers; in addition, those with ASD were participating less often in some social/recreational activities than those with ID. Although majority of children were reported to have friends, those with ASD had fewer friends that those with ID and their TD peers. Furthermore, those with ID and ASD had very poor quality of friendships. These findings indicate the importance of finding ways to encourage and provide opportunities for children with disabilities to become more involved in social activities and build friendships.

Initial Outcomes of an Emotion Regulation Intervention for Children With Autism Spectrum Disorder

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Objectives

This research investigated the acceptability and preliminary effectiveness of a manualized cognitive behaviour therapy (CBT) intervention (Secret Agent Society: Operation Regulation; Beaumont & Sofronoff, 2008) for improving emotion regulation (ER) in youth with Autism Spectrum Disorder (ASD).

Methods

To date, data includes 13 male participants, aged 8 to 12 (M = 10.3, SD = 1.2), who had IQ scores > 80 (M = 108.54, SD = 10.4) and had been diagnosed by regulated health professionals with ASD. Pre- and post-intervention measures included (a) acceptability, reported by parents on the Emotion Regulation Checklist (ERC; Shields & Cicchetti, 1997) and children on the Children's Emotion Management Scale: Anger, Sadness, Worry (CEM; Zeman, Cassano, Suveg, & Shipman, 2010); (b) child psychopathology and adaptive behaviours, reported by parents via the Behavior Assessment System for Children, 2nd Edition (BASC-2; Reynolds & Kamphaus, 2006) and the Anxiety Disorders Interview Schedule (ADIS-P-IV; Silverman & Albano, 1996); and (c) treatment response, reported by a blind clinician rater using the Clinical Global Impressions scale (CGI; Guy, 1976), severity (CGI-S) and improvement (CGI-I). Data collection is ongoing as part of a larger controlled trial.

Results

Children and parents completed all sessions (100%) and reported high satisfaction with the weekly session activities and the program overall. Therapist ratings of session activities and therapeutic alliance with children and parents were also high. Overall treatment integrity was 89.6% across 26 sessions (SD = 9.94, range = 65.4 – 100%). Parents reported significant improvements in children's emotional lability (t = 3.13, p = .005), a reduction in total psychiatric diagnoses (t = 2.80, p = .016) and diagnosis severity (t = 3.39, p = .005) on the ADIS-P-IV, and in internalizing difficulties on the BASC-2 (t = 3.18, p = .008). Blind clinician ratings on the CGI-I indicated that 69% (n = 9) children showed some level of improvement and a significant decrease in mean severity on the CGI-S (t = 3.95, p = .002). Children reported an overall decrease in dysregulation on the CEM (t = 2.14, p = .056) and increase in the ability to inhibit emotional responding (t = -2.32, p = .04.). Updated results are pending.

Discussion/Conclusions

Preliminary outcomes suggest acceptability of the intervention and potential effectiveness in improving ER and decreasing psychopathology in children with ASD. This is an important area for further investigation due to the lack of evaluations of ER interventions for youth with ASD. Longer-term implications may include translation to community-based programs that require efficient, effective, and feasible ER interventions.

Healthcare Students' Readiness for Interprofessional Learning in the Context of Developmental Disabilities

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Objectives

Equitable health care is a basic human right that must be accessible and inclusive for all individuals. The world health report 2000 (WHO, 2000) defined "human resources for health" (HRH) as including all individuals engaged in provision of health care services. Health care professionals therefore must be able to respond to both the common and additional needs of children and young people with intellectual disabilities. The purpose of this study was to explore attitudes toward readiness for this shared responsibility through inter-professional learning among groups of healthcare students at four Canadian universities.

Methods

Participants. This cross-sectional study included 594 students in Medicine, Nursing, Physiotherapy, and Occupational Therapy. All students were enrolled in entry-to-practice programs and were at different stages of degree completion.

Measures. The 19 item version of the Readiness for Inter-professional Learning Scale (RIPLS) (McFadyen et al., 2005) was included as part of a survey from a larger study examining health, education and parent factors influencing social inclusion of young children with DD (HELPS Inc). The RIPLS is divided into four subscales examining teamwork, positive and negative professional identity, as well as roles and responsibilities. An overall mean readiness score is generated as well. An adapted version of the McGill Inclusive Education Questionnaire (Daniel & Cornish, 2006) was used to rate students' perceived knowledge of and experience working with individuals with DD and perceived level of competence in working with individuals with DD.

Results

Preliminary analyses indicate that participating students were predominantly female (81%) and there was a broad range in age from 18 to 35 years. Approximately half of the students were in the second year of their degree program. Most participants (56%) had a previous university degree but 32% had entered their program from secondary school. Overall the mean RIPLS scores were quite high (M = 4.10, SD = 0.50; maximum possible score = 5.00) but scores on the RIPLS subscales varied. Internal consistency was excellent (Cronbach's alpha = .90 for the RIPLS with the exception of the roles and responsibilities subscale (Cronbach's alpha = .47). This subscale includes the fewest items (3) and also had the lowest mean score (M = 3.78, SD = 0.69). Analyses will be conducted to examine how students' perceived, knowledge, competence and experience predict RIPLS scores, controlling for gender differences.

Discussion/Conclusions

Successful collaboration requires team members to have a clear understanding of their own professional roles and responsibilities in relation to the focus for joint effort (Villeneuve, 2009). This poster will highlight healthcare students' reported readiness for inter-professional learning and the relative contributions of knowledge, experience and sense of competence to such readiness. The implications of these findings will be discussed in relation to entry-to-practice program curricula and the challenges of providing collaborative, inter-professional care for individuals with DD. Limitations of this study and directions for future research will be discussed.

The Social Inclusion of a Girl With Severe DD: A Case Study

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Objectives

Children with developmental disabilities (DD) are regularly integrated into mainstream classrooms and community settings. However, while they may be physically present in these environments, they are not always included in activities and are often ignored by their peers (Cooney et al., 2006). As a result, they often participate in social activities with adults (Solish, Perry, & Minnes, 2009). Therefore, it is important to examine the patterns of interaction that occur in school and community settings in order to understand the extent of social inclusion of these children. The Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) project explores the health, wellbeing and social inclusion of Canadian school-aged children with severe DD. One aspect of this study showed that child characteristics were related to children's social inclusion. Children in integrated or mixed settings had higher ratings of social inclusion than children in segregated settings. Finally, social inclusion occurred more frequently when activities were structured (Carvalho, Bebko, & Perry, 2014). The goal of this poster is to present findings from a case study of one child from this sample in order to gain a better understanding of her social inclusion across settings.

Methods

"Mary" is a 13-year-old girl with Down syndrome. Data were collected through a variety of sources. Mary, her parents, teachers, and community leaders were interviewed. Mary's social interactions at school and in two community settings were observed by trained research assistants, using a coding scheme developed for the GO4KIDDS study.

Results

Mary attended a public school where she was part of a special education classroom, and was involved in a dance class and camp. Her mother reported that her social inclusion in school was of mixed quality but more positive in her community settings. Three school staff members who were interviewed rated Mary as having social inclusion of mixed quality as well, although she was reported to have a group of friends with whom she socialized. Her community leaders also rated her social inclusion as being of mixed quality. She was reported to participate less than other children in camp but as much as others in dance class. The observational data suggested that Mary participated to the same degree as other children, understood the structure and expectations, and interacted well with the other children. An interview with Mary revealed that she felt that the children at school and in the community were mean to her but that the teachers and community leaders were nice.

Discussion/Conclusions

Mary was a child who took part in school and community activities. Parent and teacher ratings, along with observational data, suggested that she participated and interacted with other children in these settings. However, Mary's perception of her interactions painted a slightly different picture. The diversity of these reports reveals the importance of obtaining information from multiple sources. This allows for a better understanding of children like Mary and is an important step to take in developing strategies to enhance the lives of these children.

The North Community Network of Specialized Care Skills System Group – An Adaptation of Dialectical Behavioural Therapy for People With Developmental Disabilities Delivered by Videoconference

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Objectives

The purpose of this presentation is to provide preliminary description of an evidence-based approach to helping people with mild to moderate developmental disabilities achieve goals in their lives by learning skills adapted from Dialectical Behaviour Therapy. People with developmental disabilities residing in Northern Ontario, particularly in remote communities, often find themselves without clinical resources to assist them in overcoming challenging behaviours or challenges related to emotional dysregulation. It is for these people that The Skills System was developed by Julie Brown, MSW.

Methods

At this point in time, twelve groups of anywhere from 3–5 individuals, in addition to their support staff, attend a 12-week Skills System Group, held once weekly, by videoconference. The Group is taught via videoconference by the principle investigator (Skills Group Leader) and facilitated locally within each smaller group (breakout groups) by trained personnel – professional or paraprofessional. Each Group is two hours in duration and is organized into sections which alternate between teaching via videoconference and smaller in-group discussion. The Skills System is comprised of nine core skills and three skills system tools which helps the participants learn how and when to use the skills. Skills coaches (either paid support staff or caregivers) attend with the participants so that they familiarize themselves with the skills being learned and can provide coaching which facilitates the generalization of the skills to individuals' day to day lives. Most participants attend three cycles of 12-weeks prior to developing mastery in the Skills System. Participants undergo a contracting process prior to entrance in the group and then take part in a brief assessment using standardized psychometric instruments which are re-administered after each 12-week cycle. Retrospective behavioural outcomes will also be included in the evaluation of the project (serious occurrences, visits to the emergency department, hospitalizations, and arrests).

Results

Preliminary qualitative results will be described and the evaluation project related to this endeavour will be outlined.

Discussion/Conclusions

The North Community Network of Specialized Care Skills System Group, by virtue of its use of videoconference in combination with traditional group discussion, presents a unique and cost effective method of providing an evidence-based method of helping people with challenging behaviour, mental health difficulties, and problems with emotional dysregulation achieve their goals. It represents the preliminary model of a cross sectoral partnership in clinical service delivery.

Clinical/Research Implications & Novelty: No such skills teaching project has ever been undertaken on this scale and delivered by videoconference. The planned evaluation project is intended to demonstrate the effectiveness of the modification in mode of service delivery (hybrid videoconference/breakout group) from the original method outlined in The Skills System Instructor's Guide (Brown, 2011).